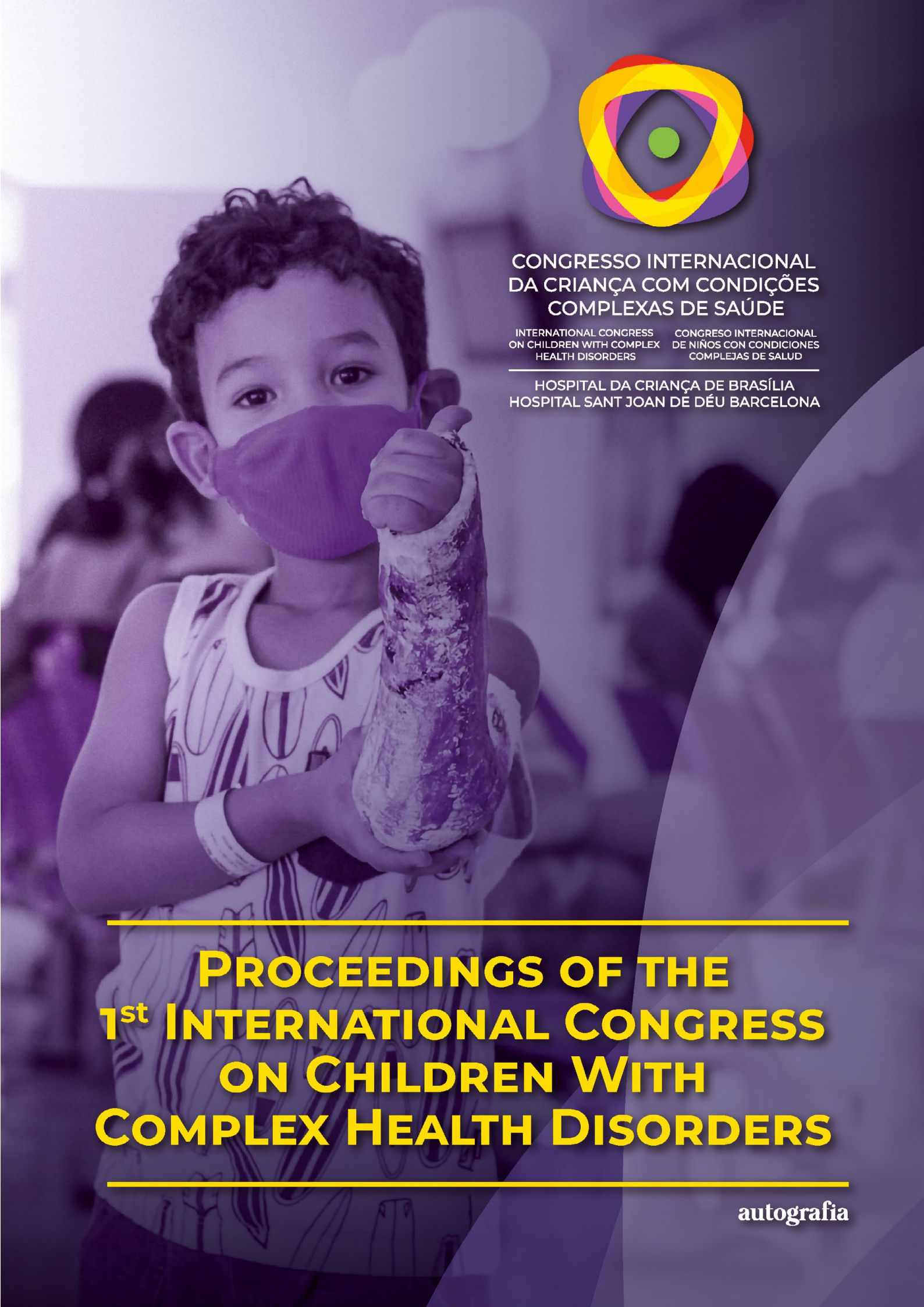

CONGRESSO INTERNACIONAL
DA CRIANÇA COM CONDIÇÕES
COMPLEXAS DE SAÚDE

INTERNATIONAL CONGRESS
ON CHILDREN WITH COMPLEX
HEALTH DISORDERS

CONGRESO INTERNACIONAL
DE NIÑOS CON CONDICIONES
COMPLEJAS DE SALUD

HOSPITAL DA CRIANÇA DE BRASÍLIA
HOSPITAL SANT JOAN DE DÉU BARCELONA

Proceedings of the 1st International Congress on Children With Complex Health Disorders

autografia

Proceedings of the 1st International Congress on Children With Complex Health Disorders

CONGRESSO INTERNACIONAL
DA CRIANÇA COM CONDIÇÕES
COMPLEXAS DE SAÚDE

INTERNATIONAL CONGRESS
ON CHILDREN WITH COMPLEX
HEALTH DISORDERS

CONGRESO INTERNACIONAL
DE NIÑOS CON CONDICIONES
COMPLEJAS DE SALUD

HOSPITAL DA CRIANÇA DE BRASÍLIA
HOSPITAL SANT JOAN DE DÉU BARCELONA

Proceedings of the 1st International Congress on Children With Complex Health Disorders

autografia

Brasília – DF
2023

REALIZAÇÃO:

International Congress on Children with Complex Health Disorders (1.: 2023: Brasília, DF)
Proceedings of the 1st International Congress on Children With Complex Health Disorders Hospital da Criança de Brasília Jose Alencar and Hospital Sant Joan de Déu Barcelona, April 24 to 28, 2023. / Committee: Valdenize Tiziani... [et al.]. – Brasília, DF: HCB, 2023.
180 p. ; 21 × 29,7 cm

ISBN 978-85-93386-17-6

1. Congress. 2. Scientific research. 3. Complex Health Disorders – Children. I. Hospital da Criança de Brasília José Alencar. II. Hospital Sant Joan de Déu Barcelona. III. Title.

CDU 001.8

Proceedings of the 1st International Congress on Children With Complex Health Disorders
International Congress on Children With Complex Health Disorders

ISBN: 978-85-93386-17-6
1ª edição, dezembro de 2023.

Editora Autografia Edição e Comunicação Ltda.
Rua Mayrink Veiga, *6 – 10° andar, Centro*
RIO DE JANEIRO, RJ – *CEP: 20090-050*
www.autografia.com.br

TECHNICAL AND SCIENTIFIC COMMITTEE

President of the Committee

Cristiane Salviano – *Hospital da Criança de Brasília José Alencar*

Committee Members

Agenor de Castro Moreira dos Santos Junior – *Hospital da Criança de Brasília José Alencar*
Aline Lordes Saliba – *Hospital da Criança de Brasília José Alencar*
Antoni Arias – *Hospital San Joan de Déu Barcelona*
Bruna Cândido Guido – *Hospital da Criança de Brasília José Alencar*
David Roe – *Hospital San Joan de Déu Barcelona*
Elisa Carvalho – *Hospital da Criança de Brasília José Alencar*
Felipe Magalhães Furtado – *Hospital da Criança de Brasília José Alencar*
Fernanda Azevedo – *Hospital da Criança de Brasília José Alencar*
Flávia Delgado Martins – *Hospital da Criança de Brasília José Alencar*
Frederico Ribeiro Pires – *Hospital da Criança de Brasília José Alencar*
Glaciele Nascimento Xavier – *Hospital da Criança de Brasília José Alencar*
Isis Magalhães – *Hospital da Criança de Brasília José Alencar*
João Lucas Cruz Souza – *Hospital da Criança de Brasília José Alencar*
José Carlos Córdoba – *Hospital da Criança de Brasília José Alencar*
Karina Mescouto de Melo – *Hospital da Criança de Brasília José Alencar*
Larissa Lemos Mendanha Cavalcante – *Hospital da Criança de Brasília José Alencar*
Luciana Sepúlveda Kopcke – *Fiocruz Brasília*
Muriel Barcelos Acioli – *Hospital da Criança de Brasília José Alencar*
Nádia Dias Gruezo – *Hospital da Criança de Brasília José Alencar*
Priscilla Lemos Gomes – *Hospital da Criança de Brasília José Alencar*
Ricardo Camargo – *Hospital da Criança de Brasília José Alencar*
Roberia Mendonca De Pontes – *Hospital da Criança de Brasília José Alencar*
Rodrigo Pinheiro de Abreu Miranda – *Hospital da Criança de Brasília José Alencar*
Suely Nascimento de Lemos – *Hospital da Criança de Brasília José Alencar*
Valdenize Tiziani – *Hospital da Criança de Brasília José Alencar*

STRATEGIC COMMITTEE

Antoni Arias – *Hospital San Joan de Déu Barcelona*
David Roe – *Hospital San Joan de Déu Barcelona*
Elisa Carvalho – *Hospital da Criança de Brasília José Alencar*
Francisco Cláudio Duda – *Instituto do Câncer Infantil e Pediatria Especializada*
Isis Magalhães – *Hospital da Criança de Brasília José Alencar*
Valdenize Tiziani – *Hospital da Criança de Brasília José Alencar*

The ICIPE – Instituto do Câncer Infantil e Pediatria Especializada and the Executive Superintendence of the Hospital da Criança de Brasília would like to express their immense gratitude to all those who somehow contributed for the International Congress on Children with Complex Health Disorders – 2023 to happen. In particular, we would like to thank the staff of the HCB, who once again dedicated a lot of effort and commitment to the success of this initiative. Our deepest thanks to all of you.

Valdenize Tiziani
Executive Superintendent Hospital da Criança de Brasília José Alencar

Summary

WORKS PRESENTED IN THE ELECTRONIC POSTER MODALITY

Presentation

With the aim of contributing to scientific advance, the Brasilia Childrens' Hospital, managed by the Institute for Childhood Cancer and Specialiazed Pediatrics (ICIPE), organized the "**International Congress on Children with Complex Health Disorders**", held between 24th and 28th April 2023, in Brasilia (DF), in a hybrid format with simultaneous broadcast of the event via a 3D, gamified platform, with the theme: "Technologies for caring and curing".

The event offered an opportunity to discuss the most recent advances in knowledge in regard to a comprehensive, humanized care for children with rare, complex and chronic health conditions. It had a total of 622 participants, of which 393 (59%) participated in person and 229 (41%) virtually.

The occasion saw the discussion of relevant themes surrounding research focused on advanced technologies for diagnosis and treatment of children and adolescents. Light technologies were also discussed in regard to advances towards a comprehensive and humanized care for children, from the perspective of the public healthcare network.

The scientific program, enhanced by the participation of 123 speakers and mediators – of whom 89 Brazilian and 34 international guests, as well as 31 instructors dedicated to short courses and technical visits to HCB.

The free theme submission had 149 summaries of scientific papers approved for presentation, of which 50 were presented orally and 99 were presented as electronic posters. The **Cata-vento Prize in Pediatric Science** awarded the best papers, with the aim of fostering the production of high-quality scientific work which demonstrates scientific rigor, research integrity, creativity, and innovation in addressing matters related to the care of children and adolescents with complex and rare health conditions.

The annals of the present congress collate the scientific papers published in the context of the event and consist of an important starting point for new scientific advances, as well as a registering the historical dimension of the knowledge and discussions surrounding tertiary pediatric care in the country.

We proudly present the summaries of the 149 papers included in the **International Congress on Children with Complex Health Disorders**".

Enjoy your reading!

Valdenize Tiziani
Executive Superintendent
Hospital da Criança de Brasília José Alencar

WORKS PRESENTED IN THE ORAL COMMUNICATION MODALITY

Advantage of caffeine in childhood early-onset ADCY5 sleep-related paroxysmal dyskinesia

Erica Beatriz dos Santos Mützenberg[1]
Ana Luísa Ayres Delduque
Aline Bezerra de Melo Filter
Ana Cecília Amâncio Vieira
Beatriz Eler de Lima
Clara Alice Yet Félix da Silva
Adriana Vieira de Moraes

Abstract

Introduction: ADCY5 gene mutations are a significant source of early-onset hyperkinetic movement disorders. Symptoms are usually present in early childhood and the phenotypic spectrum includes chorea, dystonia, myoclonus, axial hypotonia and paroxysmal dyskinesia, which can be nocturnal and painful, causing sleep fragmentation. Although there is no utterly effective treatment, deep brain stimulation (DBS) shows some improvement in reducing nocturnal dyskinesia. Recently, there have been positive reports of caffeine as a useful and noninvasive treatment.

Objective: This paper aims to assess the efficacy of caffeine in ADCY5-related nocturnal paroxysmal dyskinesia.

Methods: Structured literature PubMed search was conducted from 2018 to 2022 using the key terms ADCY5 protein, human paroxysmal dyskinesia, caffeine, sleep, dystonia, and chorea. The seven papers selected, in English, focused mainly on phenotypic spectrum, sleep disorders and the benefits of caffeine as a treatment of ADCY5-related nocturnal paroxysmal dyskinesia.

Results: Mutations in ADCY5 gene have been identified in 11% of childhood-onset hyperkinetic movement disorder. Neurological manifestations include frog-like gait in childhood, spasticity, motor developmental delay, speech delay associated with the presence of facial dyskinesia, dyskinesias characterized by brief jerks and twitches commonly classified as chorea, ballism, or choreoathetosis, paroxysmal sleep-related dyskinesias, described as violent attacks of dystonic and tonic movements during sleep that can be mistaken for nocturnal frontal lobe epilepsy. The few polysomnography (PSG) studies published reveal a correlation between abnormal movements during N2 and N3 sleep stages and low sleep efficiency due to extended sleep latency associated with dyskinesia. There have been numerous attempts for the treatment of these patients, with modest results. Some response is observed with the use of benzodiazepines (clonazepam or clobazam) and DBS of the globus pallidus internus (GPI). Furthermore, clinical reports and biological hypotheses indicate the efficiency of caffeine. The ADCY5 gene is expressed in the brain mainly in the striatum, nucleus accumbens, and olfactory tubercle, explaining the influence of ADCY5 mutations on movement control. In that regard, ADCY5 mutations mostly produce hyperactivity of adenylate cyclase type 5 (AC5), causing gain of function and, thus, hyperkinetic involuntary movements. Caffeine is an antagonist of the facilitatory adenosine A2A receptors (A2AR), which activates AC5 in the striatum. The striatopallidal neuron pathway has the highest density of A2AR and dopamine receptors of the D2 subtype (D2R). D2 receptor activation inhibits movement, reason why caffeine induced AC5 inhibition clinically improves patients with hyperactivity of this protein. Accordingly, a recent study revealed that caffeine lessened the frequency and duration of paroxysmal movement disorders, also improving baseline movement disorder and some other symptoms, including sleep quality. Overall, the use of caffeine caused consistent quality-of-life improvement for patients with ADCY5 mutations.

Conclusion: We found evidence among the articles reviewed that suggests that caffeine can effectively treat childhood-onset cases of nocturnal dyskinesia associated with ADCY5 mutations. It's been shown that it reduces dystonic and tonic movements during sleep, considerably improving patients' quality of life. Additionally, it's a much more affordable, accessible, and less invasive treatment, and should be considered as a first-line therapeutic option for this disorder.

Keywords: ADCY5 protein. Human Paroxysmal Dyskinesia. Caffeine. Sleep. Dystonia. Chorea.

1. Universidade Católica de Brasília (UCB)

Analysis of gross motor function performance based on clinical types of children with Cerebral Palsy (CP)

Taís Petrucci Boechat[1]
Amanda Larissa Oliveira Lima
Júlia Araújo Goulart
Rafaela França de Sousa
Thamiris da Silva dos Santos
Paula Chagas
Aline Martins de Toledo

Abstract

Introduction: Cerebral Palsy (CP) is the result of brain damage that can affect movement, posture, and balance, occurring in three out of every 1000 live births worldwide. In these children, the delay in the development of gross motor function has been related to dysfunctions in functionality, which can affect performance in daily living activities.

Objective: To analyze the performance of gross motor function based on the clinical types of children with Cerebral Palsy (CP) residing in the Federal District (DF).

Methods: This is a cross-sectional study with 42 children with CP aged between 2 and 17 years living in the Federal District (CAEE: 28540620.6.2005.8093). The Gross Motor Function Classification Systems (GMFCS), the Manual Ability Classification System (MACS), the Eating and Drinking Skills Classification System (EDACS) and the Gross Motor Function Measurement (GMFM) were used. The variables were analyzed using descriptive statistics, using means, medians, and standard deviations. The statistical difference between the means obtained from the results of the GMFM, GMFCS and MACS were analyzed using the Kruskal Wallis test. For all analyses, the significance of a per value lower than 0.05 and a Confidence Interval (CI) of 95% were adopted.

Results: The children evaluated had a mean age of 5.80 years (±0.829). According to the clinical type, hemiplegic children had a median level of II on the GMFCS and MACS; following the same sequence, in diplegics, levels III and II were found; quadriplegics were classified as IV and III, respectively. According to the EDACS, among all the clinical types, there was a prevalence of level I. Finally, in the GMFM, it was observed that hemiplegic children had higher levels of gross motor functions (mean: 66.60, ±3.04) compared to the clinical types diplegic (mean: 48.51, ±5.80) and quadriplegic (mean 39.91, ±5.14). In addition, through the Kruskall Wallis test, a statistically significant difference was observed between the performance of gross motor function among children of the three clinical types (H [2] = 8.498, p=0.014), as well as in the GMFCS (H [2] = 28.054, 0.001) and in MACS (H[2] = 19.217, p=0.001).

Conclusion: The results showed that, in the analyzed sample, children's performance related to gross motor function is lower as they are classified into higher levels of GMFCS and MACS, as well as the greater the extent of impairment characterized by the corresponding clinical type. As for the ability to eat and drink, no evidence was found to relate it to the level of gross motor function.

Keywords: Cerebral Palsy. Cross-sectional study. Motor Skills.

1. Universidade de Brasília (UnB)

Anti – VEGF: general understanding of the pathophysiology and pharmacology of retinopathy in neonates

Matheus Rodrigues Silveira[1]
Arthur Batista Silva
Giovana Jenifer Santana De Oliveira
Luiz Felipe Neves Frazão
Patrícia Maria Silva

Abstract

Introduction: Retinopathy of prematurity (ROP) occurs due to non-maturation and insufficient development of retinal vascularization in premature neonates, with exacerbated action of vascular endothelial growth (angiogenesis), potent and multifunctional cytokine. The picture is generated by nutritional vectors and relationships with episodes of hypoxia. In this perspective, therapy with anti-vascular endothelial growth factor (Anti-VEGF), medications that block mechanisms that form subretinal neovascularization injected into the eye, grows, and develops as the best option, since classic techniques may cause later complications, affecting the prognosis of patients. New cases of retinopathy in neonates are reported all over the world, a reality mainly in emerging countries. As a retinal disease with carcinogenic and devastating potential for patients, there is a need to expand clinical research and reduce the risks of ocular disability in these patients, in order to provide quality of life for those affected.

Objective: To understand the main concepts regarding the pharmacological management of retinopathy in neonates.

Methodology: This is a narrative review of the literature, in which PubMed and Scielo databases were used, obtaining 934 articles. Of these, 923 works were excluded due to inadequacy to the central theme and complete unavailability. Eleven articles in English and Portuguese published between the years 2018 and 2022 were selected. The descriptors in Health Sciences (DeCS) were used: Angiogenesis, Neonates, Ophthalmology, Retinopathy.

Results: According to literary research, the treatment of ROP is carried out according to the stage of the disease. At the initial stage, the risk of visual impairment and structural damage to the retina is considerably reduced. Thus, it is the main cause of blindness in children since ophthalmological follow-up after discharge from the neonatal intensive care unit is not always adequate. According to the Brazilian guidelines for the examination of premature infants with the purpose of treatment, recommended by the Brazilian Society of Pediatric Ophthalmology, the health team involved in the care of premature infants needs to investigate possible causes of the disease, enabling multidisciplinary actions and proportion of quality of life for these patients in the future. The condition of the disease is generated by nutritional vectors and relationships with episodes of hypoxia, as it is a vasoproliferative disease. In this perspective, therapy with Anti-VEGF, medications that block mechanisms that form subretinal neovascularization injected into the eye, is considered the new gold standard. Therefore, the benefits associated with handling during and after surgery are scientifically more beneficial than more classic techniques.

Conclusion: The optimization and good prognosis of therapy with Anti-VEGFs is the main reason for the growth of this medication in the last five years, in addition to contributing to inhibit angiogenesis in a way that has lower rates of complications, recurrences and better results in the short term compared to techniques already used before, such as laser. Thus, it is perceived to be a promising treatment, which can generate good results in neonates and also encourages them to have more promising and effective results in the treatment of retinopathy of prematurity. Therefore, there is an optimistic perception of this pathology as new research and results are brought to improve the conduct of these affected patients.

Keywords: Angiogenesis. Neonates. Ophthalmology. Retinopathy.

1. Universidade Católica de Brasília (UCB)

Anti-GD2: a breakthrough for the treatment of neuroblastoma

Melissa Gomes Carvalho[1]
Rinaldo Wellerson Pereira
Daniel Hígor da Silva Barros
Enzo Fraga de Aguiar
Júlia Souza Siqueira
Marcell Delgado Rodrigues
Valentina Moreira Santana

Abstract

Introduction: Neuroblastoma is a prevalent type of cancer in children, with a high mortality rate in pediatric patients. The neuroblastoma cells show an almost specific surface marker, the ganglioside GD2, which has a low expression on the surface of cells from normal tissues. The GD2 tumor specificity opened the opportunity to new venues for targeted immunotherapy.

Objective: This work presents the pros and cons of the most recent research regarding applying Anti-GD2 antibodies as a neuroblastoma immunotherapeutic drug.

Method: Exploratory qualitative review carried out by an active search in the PubMed and Scielo databases, using the descriptors: Anti-GD2, Neuroblastoma, Monoclonal Antibody, and Immunotherapy. Eleven original articles published in English since 2018 were selected for thorough reading and review.

Result: Currently, there are two anti-GD2 drugs for treating neuroblastoma: dinutuximab and naxitamab. In multimodal therapies, dinutuximab therapy (medication still under clinical trials) gave encouraging results with some cases of total remission. Naxitamab is an FDA-approved medication for treating high-risk neuroblastoma with bone or bone marrow involvement and has a significant safety and efficacy profile. Tests carried out at the Sant Joan de Déu hospital in Spain identified some adverse effects, such as hypotension, pain, urticaria, pyrexia, bronchospasm, tachycardia, nausea, cough, and vomiting. Most of the adverse effects occurred in the first cycle of treatment and decreased in subsequent cycles. Many patients also experienced acute generalized pain during naxitamab infusions, necessitating opioids for pain relief. Despite the adverse effects, the study held in Hospital Sant Joan de Déu revealed a 3-year survival rate of 82% and a survival rate free of events in 3 years of 58%. In this clinical trial 2 treatment regimens were carried out. The first was a chemotherapy regimen with Naxitamab which had a 47% remission rate and the second a Naxitamab monotherapy regimen which achieved 58% remission rate. The study started in 2017 and the follow-up is still in progress.

Conclusion: Recent data in original papers establish the Anti-GD2 immunotherapy as a promising strategy for treating neuroblastoma, in contrast to the well-established chemotherapy and radiotherapy, which present high toxicity in the short and long terms. Anti-GD2 based immunotherapy presents lower toxicity to pediatric patients and brings clinical benefits by increasing the quality of life of children while they are under treatment. However, it will be essential to address how to circumvent the resistance to immunotherapy. The evasion of the immune system that some tumor cells may present in an attempt to survive and continue to multiply are Anti-GD2 therapy drawbacks.

Keywords: Neuroblastoma. Anti-GD2. Monoclonal Antibody. Immunotherapy.

1. Universidade Católica de Brasília (UCB)

Antibody response in children and adolescents during the acute phase and over one year after SARS-CoV-2 infection

Ana Luiza Rosa Diniz[1]
Cristiane Feitosa Salviano[2]
Elisa de Carvalho[2]
Isis Maria Quezado Soares Magalhães[2]
Julia Visconti Segovia Barbosa[2]
Luciana de Freitas Velloso Monte[2]
Valdenize Tiziani[2]

Abstract

Introduction: Most individuals with SARS-CoV-2 infection develop antibodies against the virus, but there are few studies about the humoral response in COVID-19.

Objective: To describe the serological response against SARS-CoV-2 during and after one year of acute infection in patients aged 0-18 years admitted to a tertiary pediatric hospital in the first months of the COVID-19 pandemic.

Methodology: This prospective cohort study included children and adolescents admitted to the hospital from July to October 2020, in which clinical and serological data were collected during the SARS-CoV-2 acute infection and throughout the subsequent year. Serology consisted of the total pool of antibodies by Elecsys® electrochemiluminescence, collected in eight periods of time determined from the date of hospital admission. The study was approved by the Ethics and Research Committee (CAAE 31803020.3.0000.0008).

Results: A total of 122 patients with confirmed SARS-CoV-2 infection in the inpatient unit were included, 68 (55.7%) male and mean age 7.4 years (median 6.0 standard deviation ± 5.7 years). Regarding the clinical presentation, 35.3% of the individuals had flu-like symptoms, 20.5% cases presented Severe Acute Respiratory Syndrome (SARS) and 17.2% had Multisystem Inflammatory Syndrome in children (MIS-C). Twenty-seven cases (22.1%) were asymptomatic, hospitalized for other causes. Regarding the production of total antibodies against SARS-CoV-2, 85.3% of the patients had antibodies detection in at least one sample during the follow-up, and 69.6% (48/69) remained positive one year after the initial hospitalization. Patients with immunosuppressive conditions were more likely to have non-reagent serologies on admission or 365 days later, when compared to healthy individuals, being 9.5 times more likely to have non-reagent D365 serology results. Patients with SARS and/or those critically ill were more likely to have a positive D365 serology result. Severely affected patients got a 9.3 times greater chance of having a positive result after one year of the initial hospitalization. Mean titers reached their maximum value (73.25 U/ml) about 60 days after the initial infection, and then declined to the lowest mean value (18.78 U/ml) 365 days later. Patients with comorbidities or immunosuppression had lower and less durable titers when compared with severely affected patients. An important limitation of this study was the difficulty in collecting blood samples for analysis in all patients, for the whole period of time.

Conclusion: The present study demonstrated that most of the included patients had a satisfactory serological response against SARS-CoV-2 during one year after the initial acute infection, even those with chronic diseases. Despite that, there was a difference in the magnitude and duration of the immunological response of patients with and without immunosuppression, and of severely affected patients, when compared to the others.

Keywords: COVID-19. SARS-CoV-2. Serology. Antibody Formation. Seroconversion. Children.

1. Universidade Católica de Brasília (UCB)
2. Hospital da Criança de Brasília José Alencar

Applicable technology to pediatric treatment of Crohn's Disease

Ana Cecília Amâncio Vieira[1]
Clara Alice Yet Félix Silva
Aline Bezerra de Melo Filter
Ana Luísa Ayres Delduque
Beatriz Eler de Lima
Erica Beatriz dos Santos Mützenberg

Abstract

Introduction: Crohn's Disease (CD) is an autoimmune disorder characterized by the chronic inflammation that can injure any region of all the extension of the gastrointestinal tract. The main symptoms of the disease include abdominal pain, diarrhea, fever, weight loss, anemia, and weakness. It has been shown that in the past few decades, there has been an increase in the pediatric incidence of the disorder, due to the advent of Westernized diet or industrialized products that are rich in fats and carbohydrates which affect the intestinal microbiota. The role of Complementary and Alternative Medicine (CAM) and dietary therapies in increasing the quality of life of pediatric patients with CD can be highlighted.

Objectives: The present revision has the goal of investigating the function of alternative, complementary, and nutritional therapeutic methods for the CD treatment in pediatric patients, compared to the conventional pharmacological treatment.

Methods: This is a review of 5 articles published between the years 2020 and 2022, found in the PubMed and Scielo databases, and the keywords used were: Crohn's Disease and pediatric. Articles that were not written in English and those which did not have the mentioned descriptors were excluded for this review.

Results: The Inflammatory Bowel Diseases (IBD), which includes Crohn's Disease and ulcerative colitis, aggressively affects a patient's quality of life. Due to the discomfort brought by the symptoms, CD patients report difficulty studying and practicing physical exercise, fundamental activities during the development stage, besides suffering severe emotional stress. That said, CAM techniques, which include acupuncture, homeopathy, phytotherapy, meditation and yoga, may be used in order to reduce symptoms and relieve emotional discomfort. Complementary and alternative ways of treatment presented a low frequency of use among pediatric patients with CD but were classified as satisfying by adept patients. CD's conventional treatment consists of pharmacological therapy with immunomodulators and immunosuppressants, such as corticosteroids. However, the use of corticosteroids by children and teenagers presents several negative effects in skeletal health, like growth retardation and reduced bone accrual. Therefore, diet therapies are recommended to pediatric patients since enteral nutritional therapy demonstrated fewer collateral effects and equal or higher efficiency compared to conventional pharmacological treatment.

Conclusion: CD is directly related to a patient's quality of life. In pediatric cases, the answer to treatment given to the child is considerably serious, due to the numerous collateral effects of corticosteroids used by children and teenagers. Hence diet therapies could be used in replacement of conventional pharmacological treatment. Undoubtedly, in order to achieve the ideal development of all areas of the human body, it is necessary to be in homeostasis that is offered by CAM, with activities that may be adapted to become more ludic to pediatric patients. Thus, a bigger adherence to CAM by healthcare professionals is relevant to promote encouragement to pediatric patients and their support network, aiming for better treatment for Crohn's Disease.

Keywords: Crohn Disease. Complementary Therapies. Immunosuppressive Agents.

1. Universidade Católica de Brasília (UCB)

APPonco: easy access to knowledge of child and youth cancer early diagnosis

Sandra Emília Almeida Prazeres[1]
Anice Holanda Nunes
Maia Patrick da Silva Camêlo
Jackson Matos de Sousa
Juvemar Rodrigues dos Anjos Júnior

Abstract

Introduction: Early diagnosis is a primordial strategy in public health which aims at detecting illnesses at early stages on individuals and populations, facilitating definite diagnosis, treatment, and reduction of long-term harmful effects. There are several fronts which concur to its effectiveness, among them access to knowledge that, nowadays, is offered through information and communication technologies, by different institutions.

Objective: to present a mobile app for quick and safe access to information about child and youth cancer, developed by Peter Pan Association (APP – *Associação Peter Pan*), a non-governmental organization from the state of Ceará, in Brazil, which works towards increasing healing rates and improving life quality of children and teenagers with cancer.

Method: it is an experience report, a method consisting of presenting scientific and professional interventions in academic fashion, with quantitative and qualitative reports using that technological tool, based on data provided by the user's registers.

Results: APPonco, created in 2020, is the result of cooperation between the Peter Pan Association and the Federal Institute of Education, Science and Technology of Ceará, and was developed following a scientific methodology comprising the stages of requirement gathering, software architecture, test checking and validation, deployment, and software license. The tool is made available for free on Android and iOS operative systems for healthcare professionals, focusing on the training and upgrading of that public on signal and symptom detection of child and youth cancer, and for users, relatives, and caregivers, making available for them specialized digital content on child and youth cancer, and reports concerning patients' hygiene and feeding care, containing a FAQ. The tool is a pioneer in having a chat service with a pediatric oncologist in order to answer healthcare professionals' doubts. Of these, the ones who had accessed the device the most were doctors, followed by nurses, healthcare community agents, nursing technicians, psychologists, and social workers. The app report attests, until this moment, the existence of 242 healthcare professionals' registrations in the iOS operating system. The most frequent questions are about signals and symptoms, risk factors, and healing chances.

Conclusion: information and communication technologies are efficient contemporary resources to access knowledge on the healthcare area, and its impacts on good professional practices and positive health behaviors, have been verified in the case of APPonco. However, it is important to consider that child and youth cancer, even though it is a serious issue for public policies on child and youth health, is a very specific theme, with little large-scale appeal. This way, it is necessary to carry on the evaluation and continuous improvement of the app in order to broaden its applicability.

Keywords: Neoplasms. Early diagnosis. Health communication.

1. *Associação* Peter Pan

The association between Chiari I malformation and non-syndromic craniosynostosis

Ingridy Maria Oliveira Ferreira[1]
Paulo Augusto Souza Lara Leão[2]
Flávio Leão Lima[2]
Marcio Ferreira Marcelino[2]
Benício Oton de Lima[2]

Abstract

Introduction: Newborn bones are separated from one another by a fibrous tissue located in their margins, known as cranial sutures. Craniosynostosis (CS) is the premature closure of one or more sutures, causing cranial deformity, intracranial hypertension, alterations in the venous flow and possible hydrocephalus. Chiari malformation type I (CM1) is a finding in syndromic craniosynostosis. In CM1, there is compression of the cerebellum and brain stem, with a risk of health complications and even death. Adequately diagnosing this malformation can be helpful in providing care for the child. The association between syndromic CS and CM1 is already well-established. However, the association between this malformation and non-syndromic craniosynostoses has not been sufficiently studied.

Aim: Evaluate the association between non-syndromic craniosynostosis (CS) and Chiari malformation type I (CM1) in a hospital providing tertiary care in the Federal District.

Methodology: A retrospective study was conducted with children with craniosynostosis undergoing treatment at this hospital, with an analysis of computerized tomography (CT) of the head. Neurological images from patients with craniosynostosis who underwent surgery between 2020 and 2022 were reviewed. Children with syndromic craniosynostosis, such as those with Crouzon, Pfeiffer, Apert, Muenke, Saethre-Chotzen and other syndromes were included in the study, as well as patients who presented with a single closed suture. Patients whose tomography images had inadequate resolution or could not be located were excluded from the study.

Results: Of the 129 patients who underwent surgery for CS in the study period, 116 fulfilled the inclusion criteria and had their CT scans reviewed. They were divided into four groups: syndromic with CM1, syndromic without CM1, non-syndromic with CM1 and non-syndromic without CM1, representing 6%, 14.65%, 0% and 79% of cases, respectively. The presence of CM1 was only found in children with craniosynostosis involving multiple sutures. CM1 was not found in children with premature closure of a single suture.

Conclusion: Our study demonstrated the close association between CM1 and syndromic craniosynostoses, confirming its rare occurrence in children with non-syndromic CS. As CM1 can be potentially harmful to a child's health, it is recommended to investigate it by undertaking scans more detailed than CTs, in order to provide adequate treatment.

Keywords: Craniosynostosis. Chiari Malformation. Scaphocephaly. Tonsillar herniation.

1. Centro Universitário de Brasília (UniCEUB)
2. Hospital da Criança de Brasília José Alencar (HCB)

Liandra Pimentel de Castro Martins[1]
Larissa Neris Oliveira de Souza
Maria Fernanda Araujo Batalha
Amanda Einsiedel Ribeiro
Maria Carolina de Almeida Granjeiro
Verônica de Oliveira Santana
Alanna Ferreira Alves[2]

Abstract

Introduction: Autoinflammatory diseases are a rare group with a complex and yet not well-established physiopathology, caused by genetic defects in innate immunity characterized by the absence of self-reactive T cells and tissue-specific antibodies, – and its clinic and classification are already well known in the pediatric area. Due to its difficult diagnosis, it was believed that in the era of genetic testing it would be possible to identify causes, which was impossible before with clinical and laboratory data alone.

Objective: Discuss alternative conduct for diagnosing autoinflammatory diseases when genetic testing is not helpful.

Methods: A narrative bibliographic review was conducted using 6 articles written in Portuguese and English, published on BVS, Lilacs, Scielo and PubMed databases between years 2010 and 2022. The descriptors used were 'hereditary autoinflammatory diseases,' 'child' and 'diagnoses.

Results: Periodic fever episodes, skin inflammation, osteoarthritis and gastrointestinal changes are autoinflammatory diseases' manifestations. They originate from autosomal recessive genetic mutation of several genes which encode important proteins that regulate inflammatory processes. That modification triggers such inflammation and generates the rise of inflammatory markers. The ones that stood out the most genetically among these rare childhood diseases were those IL-1 mediated like Mevalonate kinase deficiency (MKD), Deficiency of interleukin-1-receptor antagonist (DIRA), Cryopyrin-associated periodic syndrome (CAPS) and TNF receptor associated to periodic syndrome (TRAPS). The diagnosis of these inflammatory diseases is rare, many of them are uncontemplated in the scientific panels, so further studies are needed. Therefore, the pediatrician must be aware of the clinical manifestations reported and suspect that, in cases of recurrent systemic inflammation, the cause may be autoinflammatory diseases. It is suggested that these patients, after excluding other causes, undergo a screening of the MEFV gene, due to the suspicion of Familial Mediterranean Fever (FMF), which manifests as generalized inflammation and can progress to amyloidosis and renal failure. In association with the exome sequencing, normally multigenic tests have low clinical applicability. However, in some cases, a wider analysis of the familiar genome is necessary to elucidate the association between genetic factors and the prompting of the disease. Thus, early diagnosis is important to begin treatment and long-term follow-up with specialist and multi-professional teams, comprising specially geneticists, immunologists, rheumatologists, and psychologists is needed. It is worth mentioning that, without the proper treatment, patients have a poor prognosis. On the other hand, with directed and appropriate treatment, although available therapeutics are scarce, prognosis is positive, and quality of life improves.

Conclusion: The early diagnosis of systemic autoinflammatory diseases is essential for a favorable prognosis. However, genetic tests – even though groundbreaking – are not always conclusive nor effective in their identification. Even with all technological advances in the medicine field, the clinical aspects are still primary for diagnosis, including systemic autoinflammatory disease, which, despite being rare, must be suspected when working with recurrent systemic autoinflammatory cases. In addition, other simple and accessible exams can help in the diagnosis, eliminating differential diagnosis and sparing financial resources, due to the high cost of genetic tests.

Keywords: Hereditary Autoinflammatory Diseases. Child. Diagnosis. Genetic. Tests.

1. Universidade Católica de Brasília (UCB)
2. Hospital da Criança de Brasília José Alencar (HCB)

Cancer diagnosis and profile of patients admitted to a pediatric palliative care service

Stefâni Soares dos Anjos[1]
Gabriella Silvestre Paiva
Beatriz Christina Luzete[2]

Abstract

Introduction: Cancer in children and adolescents is a public health problem, being the first cause of death from disease in children and adolescents in Brazil. In this context, palliative care (PC) is an approach that improves the quality of life for adult and children's patients and their families in the face of life-threatening diseases.

Purpose: This study was aimed at knowing and characterizing patients admitted and followed by the Pediatric Oncology Palliative Care Service.

Method: This is an observational and analytical study, with a cross-sectional design, with statistical analysis of data from electronic medical records in a retrospective, prospective and quantitative way, involving pediatric patients admitted to the PC service from January 2017 to December 2022. Patient data were gathered from the electronic medical record "Track Care and MV 2000" and through documents and internal reports prepared by the PC team at the Children's Hospital of Brasilia – José de Alencar. The data were compiled for further detailed analysis using an Excel spreadsheet. Data analysis was performed using the IBM SPSS program (Statistical Package for Social Sciences) in 2015. The study was submitted to and approved by the Human Research Ethics Committee.

Results: This study included 98 cancer patients aged 2 months to 21 years, with an average age of 9.14 years and a standard deviation of 5.18 years. Regarding gender data, the study was composed of 51.02% female and 48.98% male. The analysis of the diagnosis showed that 46.39% of patients were diagnosed in the Central Nervous System tumor group, followed by 34.02% of solid tumor and 19.59% of Onco-Hematological tumor. Regarding the stage of the disease at the time of admission, 48.98% were patients beyond the current possibility of treatment, followed by patients undergoing disease-modifying treatment (46.94%) and patients in end-of-life care (4.08%). As for the criteria for referral to the service, 37.76% of the participants fit into the category of high-risk CNS Tumors followed by refractory or progressing neoplasms (27.55%) and relapsed neoplasms (21.43%) and others (13.27%). In the statistical analysis, the time-spam between relapse and referral was significantly and negatively correlated to the percentage of weight loss after admission, with shorter duration between relapse and the referral being correlated with higher percentages of weight loss, which can be linked to the rapid progression of the disease and evolution to the end of life.

Conclusion: Childhood cancer is known to be a public health problem that affects the quality of life of patients and their families. Multiprofessional care from palliative care teams should be provided at early stages, regardless of disease-modifying treatment. With this, hopefully in future we could promote assistance not only to heal, but also to expand the humanized therapeutic project to improve the quality of life of children and adolescents with cancer**.**

Keywords: Palliative care. Oncology. Pediatrics. Neoplasms.

1. Universidade de Brasília (UnB)
2. Hospital da Criança de Brasília José Alencar (HCB)

Pediatric cancer and the family: study of the family dynamics and generational transmission, with pediatric cancer as an unpredictable horizontal stressor

Acimar Gonçalves da Cunha Júnior[1]
Sofia Costa Silva Duarte[1]

Abstract

Introduction: Cancer in children and adolescents (from 0 to 19 years old) is considered rare when compared to cancer in adults, accounting for between 2% and 3% of all malignant tumors registered. The theme of this thesis is pediatric cancer and its impact on family dynamics, understood from the point of view of power relations, affectivity, hierarchy, rules, roles, and communication that are established at the marital, parental, fraternal, and filial levels. Considering the complexity and severity of the occurrence of cancer in a child of a given family, an epistemological position was chosen for this research based on the assumptions of Systemic Thinking, considering the theoretical contributions of Minuchin's Structural Family Therapy, Multigenerational Family Therapy by Bowen and Carter, and McGoldrick's Family Life Cycle concept. Anchored in the concepts presented, the thesis defended here is that of the family's, regarding the relationships in their marital, parental, filial, and fraternal subsystems, identifying the family patterns of coping with the disease in the current family and the family of origin. The research was conducted under a qualitative approach. The sample was based on the fact that pediatric cancer constitutes an important unpredictable horizontal stressor, producing anxiety in the family as it progresses in time.

Objective: The general objective of the present research was to examine the meaning of pediatric cancer as an unpredictable horizontal stressor on the dynamics of all members (father, mother, and siblings) of families with a child between 4 and 12 years old with the confirmed diagnosis of cancer under treatment at the Pediatric Oncology Unit of the Hospital da Criança de Brasília (HCB).

Method: This research was approved under project number 52793021.1.0000.0029 by the Ethics and Research Council (CEP) of the Universidade Católica de Brasília (UCB) and the Institute of Children's Cancer and Specialized Pediatrics (ICIPE) number 52793021.1.3001.0144. For data collection and generation, the following were used: observation during immersion in the context, semi-structured interview, genogram, and procedure for drawing families with stories (DF-E). In this research, two analytical dimensions were considered. The first is based on concepts in the light of Bardin's proposal (2011), going through a pre-analysis process, allowing the emergence of analytical codes and categories. The second was based on the IRaMuTeQ (Interface de R pour les Analyzes Multidimensionnelles de Textes et de Questionnaires) considering the Descending Hierarchical Classification, in which segments of the text and vocabulary were correlated, forming a hierarchical scheme of classes expressed through the Similitude Analysis, making it possible to identify the co-occurrences between the words and the connection between them.

Results and Final Considerations: The results of the study revealed that pediatric cancer is an unpredictable stressor in the family life cycle, contextualized under a systemic perspective of understanding the structure and functioning of the family. When there is a child with cancer undergoing treatment, parental stress, social isolation, overprotective behaviors towards the child are identified, evidencing increased risks for marital dysfunction, as well as for psychological maladjustments in all family members, even in healthy siblings. The perspective of generational transmission of patterns of coping with the disease also looms, with potentialized affective involvement and family belief systems around the experience of faith, and increased moments of spirituality.

Keywords: Pediatric cancer. Family dynamics. Family subsystems. Transgenerationality.

1. Hospital da Criança de Brasília José Alencar (HCB)

Clinical and epidemiological characteristics of patients with parapneumonic pleural effusion admitted to a tertiary pediatric hospital in the Federal District.

Juliana Pereira Costa Justi[1]
Luciana de Freitas Velloso Monte[2]
Hugo Tadashi Oshiro Távora
Silvana Augusta Jacaranda de Faria[2]

Abstract

Introduction: Pneumonia is the main cause of mortality in children under 5 years old in developing countries. Parapneumonic pleural effusion (PPE) is the most common complication, present in about 40% of children hospitalized for pneumonia treatment. PPE has high morbidity in children and results in prolonged hospital stay.

Objectives: to describe the clinical-epidemiological profile of children and adolescents with parapneumonic pleural effusion admitted to the Pneumology ward of the Hospital da Criança of Brasília José Alencar (HCB) in 2019.

Methodology: This is a cross-sectional, descriptive, observational, and retrospective study of patients between 0 and 18 years old admitted to the Pneumology ward of HCB from January to December 2019. Clinical data were collected, and the outcomes analyzed were number of days of hospitalization, number of surgical procedures, presence of pulmonary complications in addition to PPE, number of days of O2 support, need for orotracheal intubation (OTI), number of days on OTI and discharge or death. Descriptive analysis of the data and association with qualitative variables and non-parametric tests of correlation and comparison of means with quantitative variables were performed.

Results: In 2019, 27.3% of the hospitalized patients with pneumonia at the HCB had PPE, and 54.8% were male with a median age of 3 years (SD ± 3.0y). The predominant age group was 1 to 2 years of life. Patients with comorbidities represented 17.2% of the sample. The predominant symptoms among patients with PPE were fever (97.8%), dyspnea (79.6%) and cough (79.6%). The average hospital stay was 22 days. There were other pulmonary complications associated with PPE and the need for surgical procedures for the majority of patients, with chest drainage being the most common, with an average stay in chest drainage of 12 days (SD ± 10.4d). The most commonly prescribed antibiotic was ceftriaxone (45.2% of cases). About a third of the patients required orotracheal intubation and remained intubated for 4 days on average (SD ± 7.6d). The same number of patients needed surgical re-approach. The average hospital stay was 22 days (SD ± 11.6d). There were no deaths. Factors associated with worse outcomes were the presence of other pulmonary complications and age of less than 2 years old.

Conclusion: Pneumonia and its complications represent a serious health problem for children worldwide. This study demonstrated a high complexity of patients with PPE, resulting in prolonged hospitalizations and the need for surgical procedures, in most cases. Despite the severity, there was a good response to the treatments performed, with favorable outcomes.

Keywords: Pleural effusion. Pneumonia. Child.

1. Hospital Materno Infantil de Brasília (HMBI)
2. Hospital da Criança de Brasília José Alencar (HCB)

Care for children with complex chronic conditions in the Federal District (Brazil): a pilot study about caregivers and healthcare professionals

Carolina Almeida Suassuna[1]
Natan Monsores
Lisandra Parcianello Melo Iwamoto
Marina Rehem Póvoa Braule
Natália Marques de Almeida
Denise de Lima Furlanetto

Abstract

Introduction: Complex Chronic Conditions (CCC) in childhood are multisystemic, congenital and/or acquired diseases, which have as main characteristics functional limitations, need for specialized care and dependence on technologies (MOURA et al., 2013). The person-centered clinical method is oriented to deconstruct the hierarchical mentality that the health professional is in charge and the patient passively receives the care, suggesting a perspective of shared power between the healthcare team and the patient's family (STEWART et al., 2017).

Objective: Analyze the profile and the relationship between the healthcare team and the patient's family, based on the person-centered clinical method. Specifically, we aim to revalidate the instruments Perception of Family-Centered Care – Parents (PCCF-P) and Perception of Family-Centered Care – Team (PCCF-E) in the Federal District (DF), according to aspects observed in the scientific literature.

Method: This is a pilot study with documental research and field work. We analyze data from public electronic health records (SIH – DATASUS – Ministry of Health of Brazil). Subsequently, we apply an online form via Google Form with the PCCF-P and PCCF-E instruments. All participants were invited to agree an Informed Consent Form, and then answered questions that encompassed both socioeconomic aspects, as well as the relationship between families and the healthcare team. The health professionals who participated in the study work in hospitals in the Federal District, including public and private hospitals. Parents/caregivers who answered the instrument (questionnaire) received care in 14 public hospitals and in 7 private hospitals in the Federal District.

Results: The profile of parents/caregivers who participated in the survey comprises women, aged over 30 years and mostly with higher education (59.1%). Most caregivers receive care assistance (81.8%) and spouses support (40.9%). The profile of children with CCC: 95.5% were hospitalized at least once, 45.5% of them in public hospitals and 40.9% in private hospitals. Regarding the profile of health professionals, 92.3% are female, 92.3% work in public hospitals in the Federal District. Most professionals have specific training in pediatrics (61.5%). Regarding professions, 61.5% are doctors, 15.4% are nurses and 23.1% are from other areas of healthcare.

Conclusion: The care of children with CCC is typically carried out by the female gender (CARDOSO et al., 2021). In professional settings, traditionally with a strong presence of men, the profile is changing to a relevant increase in women participation (WERMELINGER et al., 2010). In this research, we observed a female predominance in healthcare teams and in the family caregivers, which corroborates the results of Petersen (2020) and Balbino, Balieiro and Mandetta (2016). Most parents/caregivers have higher education (59.1%), in a different way from the findings of other studies (PETERSEN, 2020; BALBINO, BALIEIRO E MANDETTA, 2016). In conclusion: the research instruments tested as a pilot were successfully revalidated in the Federal District hospitals. Results regarding the profile of parents and healthcare staff agree with previous studies, but the level of education of parents/caregivers differs from the national literature.

Keywords: Complex chronic conditions. Pediatrics. Rare diseases. Caregivers.

1. Uniceplac

Challenges of multidisciplinary assessment of children with learning disabilities in the public health service

Juliana Silva Rocha Aguiar[1]
Renata Brasileiro Reis Pereira[1]
Mariana De Melo Silva Abreu
Maiara Maia de Santana
Beatriz Melo Morais

Abstract

Introduction: The Learning Disorders Guideline (DTA – Diretriz de Transornos de Aprendizagem) has been offered at the Hospital da Criança de Brasília (HCB) since 2016 and seeks to promote an interprofessional approach to children and adolescents with primary learning disorders and attention deficit and/or hyperactivity disorder, based on the specific needs of each patient and aligned with risk stratification. This protocol aims to act in an integrative and complementary way to the Health Department of the Federal District (SES/DF) health network, with regard to tertiary pediatrics.

Objective: The present work seeks to present the functioning of the Learning Disorders Guideline (DTA) at the HCB, as well as the challenges encountered in the execution of this service.

Method: Experience report, with bibliographical revisions for setting up the service and for setting up a DTA directive manual at the HCB. As well as weekly meetings of a multidisciplinary team to carry out this service and to obtain the perception of each professional on the limits and challenges related to the performance of this Guideline.

Results: Over the years of operation, the biggest challenges encountered in the operation of the DTA were: changes or departure of professionals who make up the team, resulting in a lack of evaluation of any of the interdisciplinary areas; the Covid-19 pandemic, which made it difficult to differentiate between a learning disorder from the lack of adequate stimulation resulting from the isolation of that period; medium to high complexity service, increasing the impact of these difficulties on the child's life, among others.

Conclusion: The relevance of having a Learning Disorders Guideline in the public health service is perceived, with the great value that this type of diagnostic analysis has on the development of children and adolescents. Therefore, it is necessary to identify its limits in order to overcome the challenges encountered, and promote better quality of this service, which is fundamental.

Keywords: Learning disabilities. Developmental disabilities. Public health service. Neurology. Neuropsychology.

1. Hospital da Criança de Brasília José Alencar

Child health follow-up: actions for childcare at the 9th regional health center in the state of Paraná

Gabriela Gomes Espindola[1]
Gabriela Dominicci de Melo Casacio
Katherine Slowinski Knapp
Adriana Zilly
Helder Ferreira
Rosane Meire Munhak da Silva

Abstract

Introduction: To reduce infant morbimortality it is necessary to understand the health system as a fundamental technology to guarantee integral care, establishing Primary Health Care as the central coordination point for the care network.

Objective: To describe actions for the promotion of childcare in primary care services at the 9th regional health center in the state of Paraná.

Method: Descriptive research with a qualitative approach. The study happened in seven cities from the 9th regional health center of Paraná. Mothers older than 18 years old were included, with children under six months old, born in maternity hospitals from the above-mentioned region. Exclusion criteria affected those women with clinical or mental issues that impaired their participation, however no exclusion was made. The data collection occurred from May to December 2022 through home visits and phone contacts using a structured instrument. This study was approved by the Human Subjects Ethics Committee from State University of Western Paraná, respecting the ethical precepts.

Results: The study followed 118 children under six months of age in primary healthcare services, and the results show the strategies used by healthcare workers for childcare. Concerning the stratification of risk, 87.3% of the children got classified as usual or medium, and 11% as high risk. Regarding child-care consultations, 27.1% appeared for more than six appointments, 17% from five to six, 22.9% from three to four, 22% from one to two, and 11% didn´t attend any appointments in primary healthcare units. Home visits reached 7.6% of participants. Another study indicated that home visits do not occur for all children, despite being recommended by the Paraná Mothers Network (Rede Mãe Paranaense)– the network of maternal and child healthcare. The same happened with telehealth, achieving 11.9% of children. When asked about their health services of choice, 56.8% of the mothers use the primary care units. Among healthcare workers who carried out most appointments, 19.5% are general practitioners and nurses, followed by pediatricians (16.1%). Neonatal screening tests refer to an important strategy for early diagnosis. The Guthrie test and the newborn Hearing test were the most accomplished, with 99.1% each. The Pulse oximetry test and the red reflex test were 86.4% and 88.1% of cases, respectively. The neonatal Tongue screening test achieved only 59.3% of the children. Another action to guarantee child health is the immunization. In this study, the complete vaccination schedule occurred for 63.6% of the children while 36.4% had vaccination delays.

Conclusion: It seemed necessary to have activities for health promotion and prevention, because actions recommended by the Ministry of Health and the Paraná Mothers Network did not reach all children monitored.

Keywords: Primary healthcare. Child health. Health promotion. Pediatric nursing.

1. Universidade Estadual do Oeste do Paraná (UNIOESTE)

Co-designing a digital care model in Complex Pediatric and Chronic Palliative Care through action-participatory research.

Lucía Peñarrubia San Florencio[1]
Sílvia Ricart Campos
Sergi Navarro Vilarrubí
Arnau Valls Esteve
Cristina Ruiz Herguido
Daniel Toro Pérez

Abstract

Introduction: The Complex Chronic Patient and Pediatric Palliative Care Service (C2P2 Service) of Barcelona Children's Hospital Sant Joan de Déu is an interdisciplinary service whose main objective is to improve quality of life (QoL) of patients and their families. The care provided by the C2P2 service takes place wherever the patient and family are, generating needs that the use of digital technology could resolve. Complementing the current care with new digital tools would help to provide security and support to those families who decide to perform the end of life at home. The complexity of C2P2 patients, distributed throughout the territory, yields other needs since these patients require different levels of care and the involvement of multidisciplinary teams. The use of algorithms developed with artificial intelligence can stratify these patients and predict the risk and needs for each one, providing personalized care and improving the QoL of those patients. The AICCELERATE – Smart Hospital Care Pathway Engine project will allow the development of technological solutions (social robots, telemonitoring) to achieve the digital transformation of the C2P2 service, creating a new model of care to improve both the experience of the patient and their families and the efficiency of the provision of health services. In addition, it will also contribute to improve service professionals' experience.

Objective: Co-design a hybrid model of care, combining traditional and digital tools, with the assistance of families and professionals of the C2P2 service.

Method: This study will apply a qualitative methodology based on Participatory Action Research (PAR). Families and professionals of the C2P2 service will partake, and the results obtained will be used to design the different technological solutions for the AIccelerate project. A 5-step approach is proposed: 1. Diagnosis of the situation. 2. Action planning. 3. Development of the action. 4. Simulation and piloting of prototypes. 5. Final implementation.

Results: The following briefly describes the first stage results obtained from different interviews and focus groups, and stage 2 is under development. Most participants are unfamiliar with technological devices beyond tablets and smartphones for recreational use. However, they are interested and describe the different proposals of TICs in health as valuable and comfortable. They emphasize their interest in reporting information in acute episodes, providing support to secondary caregivers as well as using it as an educational tool. The professionals are more reluctant about the use of new digital tools. They highlight the following as critical points: specific learning required to use the tools implemented, dimensioning the time spent in this learning, and their daily use. In addition, the professionals believe that implementing digital tools can increase workloads and suggest the involvement of team members in developing digital tools to avoid those issues.

Conclusion: The participation and predisposition of families to the use of new digital technologies is greater than that of the professionals involved, in agreement with the previous results obtained in other projects related to the digitalization of pediatric units. The involvement of professionals in developing digital tools will be essential to successful implementation.

Keywords: Community participation. Palliative care. Telemedicine.

1. Hospital Sant Joan de Déu

Digital history validation based on childhood urinary and bowel symptoms experience

Lilhian Cristine Fernandes da Fonseca[1]
Cristiane Feitosa Salviano[2]
Gisele Martins

Abstract

Introduction: Bladder and Bowel Dysfunction (BBD) is a urological condition in which there is an association between an intestinal symptom, in most cases represented by Functional Intestinal Constipation and one or more of the Lower Urinary Tract Symptoms (LUTS), with the BBD prevalent in school-aged children.

Objective: To validate the script and storyboard content of a digital story developed based on the experience of urinary and intestinal symptoms in children aged 6 to 12 years, with a view to supporting the communication process with professionals working in the field of pediatric urology.

Method: Methodological study for content validation of the script and digital history storyboard by professionals with expertise in the area, through a research evaluation instrument. Study approved by the Research Ethics Committee of the Faculty of Health Sciences, of the Universidade de Brasília, under number 3,133,554, in February 2019.

Results: The values of the items calculated separately were averaged, so that all the CVIs that were calculated separately were added and divided by the number of items considered in the evaluation, obtaining an average of 0.91. The instrument as a whole has a validation index greater than 0.90, in line with recommended values.

Conclusion: The present research contributes to the expansion of the communication of the child with bladder and bowel disorders, allowing a more effective expression of symptoms with the health professional and improving treatment strategies. As next steps for the research, a second round of validation is proposed. It's also important as a future perspective that the material is validated by the target audience of the research, i.e. parents and children themselves, which will be carried out shortly by the research group that this study is linked to.

Keywords: Cystic fibrosis, Epidemiology, Phenotype, Children's Health, Adolescents' Health.

1. Universidade de Brasília (UnB)

2. Hospital da Criança de Brasília José Alencar (HCB)

Educational technology in peritoneal dialysis: experience with a board game

Alexciana Farias Batista[1]
Cristiane Feitosa Salviano[1]

Abstract

Introduction: Chronic Kidney Disease (CKD) is the progressive loss of kidney function for a period of more than three months. The prevalence of CKD in pediatrics is lower than in adults, and data from the 2019 census of the Brazilian Society of Nephrology indicate that 1.2% of chronic renal failure patients on dialysis are aged between 1 and 19 years. Peritoneal dialysis (PD) is a dialysis modality that gives the patient and family greater freedom given that it can be performed at home by those responsible and/or the patient. For this ability, the nephrologist nurse trains the family for the necessary care. In pediatrics, the patient has a limited role in the proposed teaching activities, but it is essential that this population is trained to become active agents of their own care. Few studies address training and self-care strategies for children and adolescents in PD. Considering that a teaching approach aimed at children and adolescents must be consistent with the age group and cognitive/developmental level, it is understood that the use of purpose games can be a strategy that stimulates and involves the patient with a friendly language. Thus, they are tools that can be used in the various teaching-learning processes.

Objective: To describe the experience of peritoneal dialysis training with a 12-year-old teenager using a thematic board game in a specialized pediatric hospital in the Federal District.

Method: Report of a training experience for performing a peritoneal dialysis therapy directed at a teenager from the peritoneal dialysis program at the Hospital da Criança de Brasília José Alencar.

Results: 12-year-old teenager was trained in 8 meetings to perform her home peritoneal dialysis sessions. The training took place in the peritoneal dialysis training room, mostly in the morning shift. At the end, health education technology was applied, in a board game format, designed to capture the level of knowledge absorbed by the patient during the training period and thus confirm her ability to carry out the therapy independently at home, with parental supervision, especially at the beginning.

Conclusion: It was possible to train the patient for self-care with regard to PD. It was then verified the possibility and relevance of shared care management between parents and/or caregivers and patients. In view of this, it is important to prepare adolescents to actively participate in their care, which provides greater adherence to treatment. It is essential to choose appropriate teaching methods for the age group, aiming at clear language and meaningful learning. The board game proved to be a valuable educational tool, but it is recommended to apply it in other cases so that it can be validated and improved. It is believed that this report will contribute to having more health professionals, especially nurses, developing studies to train adolescent patients with chronic diseases through educational technologies based on games, because, in addition to involving them and facilitating their understanding and knowledge about the topic addressed, it is a low-cost strategy.

Keyword: Educational. Technology. Health education. Teaching materials. Adolescent. Peritoneal dialysis.

1. Hospital da Criança de Brasília José Alencar (HCB)

Evaluation of continuous glucose monitoring program with children and adolescents of the Federal District, Brazil

Bruna Alexandra Rehbein[1]
Sarah Rocha Margittay[1]
Gustavo Henrique Lopes de Aguiar[1]
Felipe José Albuquerque de Oliveira[1]
Carol Leite Vasconcelos[2]
Fernanda Vieira de Souza Canuto[3]
Michele Delarmelina dos Reis Borba[3]

Abstract

Introduction: Type 1 diabetes mellitus (T1DM) is a chronic disease characterized by insulin deficiency. Approximately 64.6 thousand children and adolescents (ages ranging 0-14) have the condition in Brazil. Aiming at the reduction of acute and chronic complications of the disease, the Department of Health of the Federal District in Brazil (Secretaria de Saúde do Distrito Federal –SES/DF) has implemented the Continuous Glucose Monitoring Program (CGMP), which provides 2 FreeStyle Libre® glucose monitoring (GM) sensors for each patient, monthly. To be included in CGMP, patients must meet the following criteria: to be treated with analogue of basal and bolus insulin in adequate levels, to document blood glucose during the past 90 days before the medical request, to participate in educational meetings on diabetes, to have glycated hemoglobin (A1C) levels 8% in the last 6 months and to do carbohydrate counting. After a 6-month follow-up, those who meet the requirements are re-registered in the program.

Objective: To assess the number of children and adolescents in the Continuous Glucose Monitoring Program.

Methodology: This is a cross-sectional study using data provided by the CGMP team in the SES/DF with approval of the Fundação de Ensino e Pesquisa em Ciências da Saúde –FEPECS ethics committee in research (doc. nº 5.475.356). The analyzed variables were the number of benefited children and adolescents, their age and how long they used a GM sensor in the period of 2020 to 2022.

Results: Since the Program has started, a total of 583 patients have had access to GM sensors, of which 79 (13,5%) were children and teenagers with T1DM. It is valid to point out that 9 out of 79 patients were users of a continuous insulin infusion system (CIIS). In this analysis, the 79 pediatric patients in CGMP were divided into three groups: group A, with 5 patients aged 4-8 group B, with 26 patients aged 9-13 and group C, with 48 patients, aged 14-18. After 6-month follow-up, 60% of group A 23.1% of group B and 18.75% of group C had reached the targets for glycemic control according to the criteria for continuity. Therefore, only 22.78% of patients were reaccepted in the program, of which 11.11% make use of CIIS at the time of writing. Regarding this information, the participation of caregivers is more active and needed in the treatment of the youngest group: it is believed that age and other variables, such as painless glycemia taking, real-time visualization of blood sugar and early patient education might have contributed to greater adhesion of group A. It is worth mentioning the difficulty in gathering recent and quality epidemiology information on the number of patients with T1DM, hence the lack of figures on the program's reach.

Conclusion: Through CGMP, children had a chance to play an active role in the treatment, in addition to continuous and painless glycemia assessment, receiving patient education as well. Nevertheless further analysis is needed in order to clarify the reasons for low adherence to the Program, so that CGMP can benefit more patients.

Keywords: Diabetes mellitus. Glycemic control. Glycemic index. Pediatrics. Blood Glucose Self-Monitoring. Outcome assessment.

1. Escola Superior de Ciências da Saúde-ESCS
2. Universidade Católica de Brasília (UCB)
3. CEDOH/SES, ESCS/FEPECS-DF

Evaluation of minimal residual disease in children with acute lymphoblastic leukemia in therapy at the children's Hospital of Brasilia

Robéria Mendonça de Pontes[1]
Ana Beatriz Gouveia[1]
Ricardo Camargo[1]
Estefânia Rodrigues Biojone[1]
Agenor de Castro Moreira dos Santos Júnior[1]
Pérola de Oliveira Magalhães[1]
Felipe Magalhães Furtado[1]

Abstract

Introduction: Acute Lymphoblastic Leukemia (ALL) is the most common type of cancer in children, representing from 75 to 80% of all childhood neoplasms, with an overall survival rate of approximately 90%. Minimal Residual Disease (MRD) is an important predictor of relapse in ALL. In 2018, the Children's Hospital of Brasilia (HCB) included bone marrow (BM) MRD monitoring for risk stratification and follow-up at D15, D33 and D78 of the protocol. In the present study, BM samples of patients with ALL were analyzed to determine MRD profile and further patient outcomes.

Objectives: Determine MRD profile in children with ALL treated at the HCB Evaluate MRD as a prognostic factor.

Methods: Patients with ALL, ages 1 to 17, treated at HCB with the BFM 2009-adapted protocol between June 2018 and December 2022 were included. Exclusion criteria were Down syndrome history of chemotherapy for other cancers and relapse at admission (diagnosis from another institution). BM MRD samples were collected at the Hospital facilities and immunophenotyping was analyzed using FACSCanto flow cytometer and Infinicyt software at the Translational Research Laboratory. A total of 309 BM samples were analyzed from 117 patients at different time points during follow-up (116 at D15, 108 at D33 and 85 at D78), which is explained in part by the change in the protocol. Statistical analysis was made using SPSS software. Approval by the Ethical Committee (number: 85960218.5.0000.5553).

Results: Of 117 patients included, 51 were female and 66 were male, 110 (94%) were diagnosed with B ALL and 7 (6%) with T ALL. For risk stratification, the following criteria were used: patients, between 1 and 6 years old, leucometry at diagnosis < 20000/mm3, with MRD < 0,1% at D15 and < 0,01% at D78 and no high risk factors were classified as Low Risk (LR) patients with MRD D15 > 5%, MRD D78 > 0,01% or other high-risk factors (t(9 22) or t(4 11)) were stratified as High Risk (HR) patients who did not meet the criteria above were stratified as Intermediate Risk (IR). Twenty (17,1%) patients were classified as LR, 77 (65,8%) patients were classified as IR and 20 (17,1%) were classified as HR. Were observed 19 (16,2%) deaths, 4 (3,4%) relapses and 2 (1,7%) losses of follow-up. The number of deaths was greater in HR patients: 19 patients deceased throughout this study, 9 (47,4%) were classified as IR and 10 (52,6%) were HR no LR patients died.

Conclusion: Even though MRD was just recently added to the ALL-treatment protocol at this institution, it has been confirmed as an effective and sensitive approach for ALL monitoring and has also shown to be a valuable prognostic factor for those patients.

Keywords: Acute Lymphoblastic Leukemia. Minimal residual disease. Flow cytometry.

1. Hospital da Criança de Brasília José Alencar (HCB)

Evolution of children and adolescents one year after the diagnosis of multisystem inflammatory syndrome associated with SARS-CoV-2 during the pandemic

Julia Visconti Segovia Barbosa[1]
Gabriela Lucia de Oliveira e Silva
Fernanda Kiyomi Chaves
Aline Garcia Islabão[2]
Marne Rodrigues Pereira Almeida[2]
Caroline Graça de Paiva[2]
Luciana de Freitas Velloso Monte[2]

Abstract

Introduction: In December 2019, the SARS-CoV-2 virus ushered a devastating pandemic, which initially appeared to spare children and adolescents from severe manifestations. As of mid-April 2020, a few reports drew attention to increased hospitalizations of children and adolescents with clinical features similar to Kawasaki Disease (KD). This condition, later called Multisystem Inflammatory Syndrome in children (MIS-C), is a result of a hyperinflammatory state related to recent infection by the SARS-CoV-2 virus and is associated with prominent gastrointestinal and neurological symptoms, in addition to cardiac involvement, with myocarditis and coronary artery aneurysm being its main complications. As it is a new and rare disease, there is still a shortage of studies that explore the clinical and epidemiological aspects and, mainly, the evolution of patients with MIS-C, its outcomes and possible sequelae.

Objective: To describe clinical, laboratory and imaging evolution, outcomes, and complications one year after the diagnosis of MIS-C in children and adolescents admitted to a tertiary public hospital in Brazil.

Method: Descriptive retrospective cohort of the epidemiological and clinical-evolutionary aspects of these patients, submitted and approved by the Ethics and Research Committee (CAAE 31803020.3.0000.0008).

Results: Of the 122 patients hospitalized with confirmed infection by SARS-Cov-2 in the defined period, twenty-one (17.2%) were diagnosed with MIS-C, with a mean age of 8.4 years, in which thirteen (61.9%) were female. Of the 21 patients included in the study, four (19.0%) had previous comorbidities: two had asthma, one juvenile idiopathic arthritis and one epilepsy and KD. Among the symptoms presented at hospital admission, fever is omnipresent (100%), as it is part of the diagnostic criteria for the syndrome. Seventeen patients (81%) had abdominal pain, associated with diarrhea (53.4%) and vomiting (66.7%), in addition to skin changes (81.0%), manifesting predominantly as pruritic maculopapular rash on the trunk and limbs. Dyspnea was present in ten patients (47.6%). Thirteen (61.9%) needed support in the Intensive Care Unit during their initial hospitalization, with a mean length of stay of 10.3 days (SD ± 7.9). All twenty-one patients (100%) evaluated were primarily hospitalized for an infectious cause. Nineteen of these (90.5%) underwent outpatient follow-up at the same hospital after discharge, with an average of 4 consultations in the period studied, predominantly accompanied by Rheumatology (100%). Seven (33.3%) remained with symptoms after discharge and eighteen (90%) used continuous medication for the sequelae of the disease, not exceeding 6 months after discharge. There were no deaths in the evaluated period. With regard to imaging tests, seventeen (81%) followed up with an echocardiogram over the period of a year. Among these, nine (52.9%) remained with echocardiographic alterations for up to 7 months after discharge, predominantly mitral insufficiency (66.7%) and three (33.3%) evolved with echocardiographic resolution.

Conclusion: Despite the criticality and complexity of the syndrome, the evolution over the subsequent year was quite favorable for the patients in the study, with no deaths, most of the patients being asymptomatic after discharge and with normalization of complementary exams over subsequent months.

Keywords: SARS-CoV-2 infection. Multisystem inflammatory syndrome in children. Clinical evolution.

1. Escola Superior de Ciências da Saúde (ESCS)

2. Hospital da Criança de Brasília José Alencar (HCB)

Experience of children and adolescents undergoing bone marrow transplantation in the context of oncological disease

Camila Dornelas de Carvalho e Garófalo[1]
Aline Oliveira Silveira

Abstract

Introduction: Bone marrow transplantation (BMT) consists of an aggressive therapy that aims to correct a qualitative or quantitative cell defect by replacing the diseased bone marrow with healthy stem cells. Its need is often the result of failure in the conventional treatment of various diseases. The oncological context of BMT in pediatrics brings a series of challenges to children and adolescents, making it necessary to understand their experiences in order to adequately meet their needs.

Objective: To understand the experiences of children and adolescents submitted to bone marrow transplantation in the context of oncological disease.

Method: Qualitative study, adopting the theoretical perspective of the Symbolic Interactionism and the methodological approach of Narrative Research. The data collection took place by filling out a specific instrument in order to determine the participants' profile, and audio-recorded comprehensive in-depth interview. Study participants were children and adolescents aged between 6 and 17 years who underwent bone marrow transplantation and were undergoing post-BMT follow-up at the institution chosen as the study site. For the analysis of the qualitative data obtained through the in-depth interviews, we opted for the analysis of narratives from a holistic perspective with an emphasis on content.

Results: 3 adolescents and 4 children after BMT participated in the study. From these, 2 underwent allogeneic transplantation and 5 the autogenic type. Four thematic categories were identified: perceptions about the bone marrow transplantation process, feelings of children and adolescents regarding the bone marrow transplantation process, needs and difficulties during the bone marrow transplantation process, strategies for coping with challenging situations, and the post-transplant period and its expectations. Understanding the experience of children and adolescents undergoing BMT in the context of an oncological disease reveals how children perceive and assign meaning to their experiences. In general, the experiences were described as difficult, challenging, but with hopeful expectations for the future.

Discussion: Other studies, although with different objectives, recorded similar experiences regarding the difficulties faced in the transplantation process. The importance of starring the child as a spokesperson, capable of self-reporting their health status and experiences was also identified.

Conclusion: The research revealed that the studied experience is complex, painful, and permeated by countless challenges. The discomforts experienced surpassed the physical body, also affecting the participants' minds, feelings, and social interactions. The wealth of reports reinforces the importance, need and urgency to listen and consider the narratives of children and adolescents with the ultimate goal of improving the comprehensive and unique care in the context of BMT and oncological diseases.

Keywords: Bone marrow transplantation. Life-changing events. Adverse childhood experiences. Child. Adolescent.

1. Universidade de Brasília (UnB)

Experiences of mothers of chronic children dependent on technologies in a pediatric intensive care unit

Brendo Vitor Nogueira Sousa[1]
Aline Oliveira Silveira
Elenilda Farias de Oliveira
Gisele Martins

Abstract

Introduction: Technology-Dependent Children are those who live with a chronic condition, with a fragile state of health, subject to a high level of medical complexity and dependence on technological products essential to their survival. These children require continuous, long-term, specialized care to maintain their health, making them an example of the subgroup of Children with Special Health Needs.

Objective: To describe the subjectivity of the repercussions of hospitalization of chronic technology-dependent children in a Pediatric Intensive Care Unit from the perspective of the main caregiver.

Method: Qualitative-descriptive study carried out with 11 mothers of Chronic Technology-Dependent Children. Data were collected through semi-structured, recorded interviews, which were later transcribed, coded and subdivided into categories. Thematic Content Analysis was used as an analysis strategy.

Results: The analysis of the narratives allowed the identification of four categories: I – experiencing prolonged hospitalization and family distancing, portrays the separation from other family members, leading to changes in family dynamics; II – maternal suffering, such as negative emotional states, anguish, fear, frustrated expectations and overload; III – difficulties and needs, related to accepting the child's condition, financial problems, absence of a support network and hospital isolation in addition to the pandemic, that further accentuated the difficulties, such as financial problems, difficulties in multidisciplinary monitoring, suspension of surgeries and difficulty in providing doctor care; and IV – coping strategies, established to ease problems such as attending chapel/mass, walking outside the hospital, changing caregivers, doing manual activities, reading and exchanging experiences with other mothers.

Conclusion: Nursing care is of fundamental importance as a support network in this moment of deconstruction of the health-disease process, as there is a need for social intervention so that the mother and child have psychosocial stability outside the hospitalized context.

Keywords: Hospital assistance. Childcare. Nursing care. Chronic disease. Family.

1. Universidade de Brasília (UnB)

Functional status of children with complex chronic conditions upon discharge from the pediatric intensive care unit

Lisandra Parcianello Melo Iwamoto[1]
Natan Monsores de Sá
Vanessa Campes Dannenberg
Marília Aires de Oliveira
Chiara Falquetto
Regiane Rabelo
Kamila França

Abstract

Introduction: The greater life expectancy of children with chronic conditions has significantly increased the number of patients admitted to Pediatric Intensive Care Units (PICU). Thus, assessing the functional status of children with chronic conditions at PICU discharge has become part of long-term care strategies for these children and their families. The Functional Status Scale (FSS) has been applied in some PICUs at admission and discharge to evaluate and monitor children's functional statuses. The FSS is an instrument that assesses six health domains: mental state, sensory, communication, motor function, eating, and breathing. The domains have a score ranging from 1 (normal) to 5 (very severe dysfunction). Total scores can range from 6 to 30, with lower scores indicating better function. Thus, a 6-7 indicates a normal functional status, 8-9 slightly abnormal, 10-15 moderately abnormal, 16-21 severely abnormal, and a score greater than 21 indicates a very severe abnormal functional status.

Objective: To characterize the functional status of patients with complex chronic conditions at PICU discharge using the FSS.

Methods: A documentary, retrospective study was carried out. A total of 349 patients were evaluated through the FSS at the PICU discharge. We selected and analyzed data from 68 children with complex chronic conditions classified with FSS total scores 08. The presence of complex chronic conditions was defined according to the pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation by Feudtner et al1. 1. Feudtner, C. et al. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. BMC Pediatrics. v. 14, n. 1, p. 199, 2014.

Results: Our sample consisted of 68 patients with complex chronic conditions, including 27 patients with neurological conditions, 07 with cardiovascular conditions, 24 with congenital anomalies or genetic defects, 09 born premature, 01 with liver transplant. Of these, 54% were male, with a mean age of 3 years. Thus, 13.24% had mild dysfunction, 51.47% had moderate dysfunction, 27.94% had severe dysfunction, and 7.35% had very severe dysfunction. The median of the global FSS score was 13 [8 – 28], with higher scores in the domains 'eating' 4 [1 – 5], 'motor function' 3 [1 – 5], 'respiratory status' 2 [1 – 5] and 'communication' 2 [1? 3.5]. We did not find functional impairment in the 'mental state' or 'sensory function' domains.

Conclusion: The application of the FSS allowed the characterization of the functional status of patients with complex chronic conditions discharged from our PICU in 2020. Our findings demonstrate a greater prevalence of moderate dysfunction in global functionality and higher functional impairment, mainly in 'eating' and 'motor function'. Therefore, it is essential to follow up with these patients after discharge from the PICUs to verify their functional demands and to guarantee the continuity and quality of the care offered to this population, reducing readmissions in the PICUs.

Keywords: Pediatrics. Chronic disease. Intensive care units. Functional status. Physical functional performance. Comprehensive healthcare.

1. Secretaria de Saúde do Distrito Federal (SES-DF)

Genomic surveillance of SARS-CoV-2 variants of interest in a pediatric hospital

Marina da Costa Ribeiro[1]
Agenor de Castro Moreira dos Santos Júnior[1]
Bruna Cândido Guido[1]
Larissa Lemos Mendanha Cavalcante[1]
Brenno Vinicius Martins Henrique[1]
Helder Andrey Rocha Gomes[1]
Ricardo Camargo[1]

Abstract

Introduction: COVID-19 is a contagious illness caused by the SARS-CoV-2 virus. Its symptoms range from asymptomatic to Severe Acute Respiratory Syndrome and multiple organ dysfunction. The RT-PCR test is the gold standard for identifying the virus in respiratory secretions. In response to the pandemic, the Translational Research Laboratory (LPT) at Hospital da Criança de Brasília (HCB) implemented the qRT-PCR test to detect the virus in patients and patients' guardians as the hospital treats patients with unique clinical complexity such as immunodeficiencies, those using chemotherapy, among other conditions that fall within the risk group for SARS-CoV– 2. The test is also used as a diagnostic tool for employees with suspected COVID-19, as well as for mapping asymptomatic cases, allowing for early isolation and medical leave, avoiding the spread of the virus among hospital employees. Like other RNA viruses, SARS-CoV-2 changed through mutations along the pandemic making its genomic surveillance crucial for understanding the evolution of the virus and monitoring the spread of potentially more transmissible or dangerous variants.

Objective: This work aims to demonstrate the significance of genomic surveillance of SARS-CoV-2 in a pediatric hospital and its impact on the public health system, as it allows for the monitoring and understanding of the evolution and spread of the virus.

Methods: Real-time PCR was used to diagnose positive COVID-19 cases and partial Sanger sequencing of the S gene, which codes the virus Spike protein, was used to identify mutations that determined the variants which were circulating in the hospital. For the identification of the variants, the sequences were compared to the data available on the CoVariants Platform (https://covariants.org).

Results: From May 18, 2020, to January 31, 2022, HCB executed 20,620 tests, of which 8,482 were on patients, 7,167 on patients, relatives, and 4,962 on employees. With the emergence of new variants, HCB identified the need for genomic surveillance of SARS-CoV-2 as it is crucial for understanding the evolution of the virus and monitoring the spread of potentially more transmissible or dangerous variants. Between January 2021 and December 2022, LPT identified 1.171 positive cases of COVID-19. Out of these cases, 421 were selected for sequencing, to determine their viral genetic makeup, leading to the identification of 13 different known variants of interest. This information is crucial for developing effective strategies to control the spread of the virus and minimize its impact on the care of the hospital patients.

Conclusion: Since the beginning of the COVID-19 pandemic, healthcare institutions worldwide have been working tirelessly to provide the best care to patients and keep their staff and visitors safe. Genomic surveillance of COVID-19 variants is crucial for detecting new variants, monitoring their spread, assessing vaccine efficacy, and improving understanding of virus biology. The data obtained from the genomic surveillance is crucial for the public health system to develop effective strategies for controlling the pandemic and ensuring that vaccines and treatments remain effective against new variants.

Keywords: COVID-19. Variants. Genomic. Surveillance. Sequencing.

1. Hospital da Criança de Brasília José Alencar (HCB)

Growth characterization of children with severe asthma followed up at a university hospital

Paula Helbourn Bastos[1]
Marcela Nogueira Silva Pestana
Ana Clara Ramalho Gomes
Carmen Livia Faria da Silva Martins[2]

Abstract

Introduction: Asthma is a very prevalent disease, characterized by an obstructive pattern, with chronic inflammation and hyperreactivity of the airways, resulting in symptoms such as wheezing, dyspnea and cough. It can be divided into mild, moderate, or severe asthma, depending on the level of treatment required. In severe asthma, symptoms are more severe and high doses of inhaled corticosteroids (ICS) are used, which increases concerns about adverse effects. Although there are studies that reveal an association between growth disorders, asthma, and the use of IC, the relationship is not yet consolidated, since there is divergence in the literature, making it important to investigate a possible association between these factors.

Objective: Evaluate the effect of severe asthma on children being followed up at the University Hospital of Brasília (HUB) over the last three years and its possible consequences on their height growth.

Method: Descriptive, observational, cross-sectional study conducted at the HUB by searching for data in the medical records of patients treated at the pneumopediatrics outpatient clinic, from January 2018 to December 2021. 24 patients aged 5 to 10 years, 11 months and 29 days, with severe asthma, were included. Then, they were registered, using a Google Forms spreadsheet, containing age, gender, origin, weight, height, BMI, Z-score: weight/age, height/age, BMI/age, asthma control status and daily dose of inhaled corticosteroid. Asthma control status was assessed using the Asthma Control Test (ACT), for the assessment of height, weight and BMI, the World Health Organization (WHO) charts were used. For statistical analysis and graphing, the tidy verse package (version 1.3.1) in Software R (version 4.1.2) was used.

Results: The average age was 7.38 years, 50% female and 50% male, the average daily dose of inhaled corticosteroid was 556.25 mcg/day, and weight was 29.59 kg. Regarding asthma status, 16 patients had controlled asthma and 8 had uncontrolled asthma. The average height was 127.88 cm, being 2 with height outside the normality and 22, normal height for the age. When comparing the variables controlling or not controlling asthma in relation to height, the two-tailed probability of its occurrence due to chance (p) is 0.667. Analyzing the BMI, 7 were classified as inadequate and 17 as adequate. When comparing the variables controlling or not controlling asthma in relation to BMI, p was equal to 1.000 and relating height and BMI with higher IC doses used, p was 0.507 and 1.000, respectively.

Conclusion: From the data presented, there were no statistically significant relationships since the two-tailed probability of occurrence due to chance was greater than 0.05 in all variables and, therefore, greater than the limit of 0.05 determined for statistical relevance. Thus, it cannot be stated that the presence of severe asthma, the use of corticoid doses greater than 400 mcg or the degree of clinical control of the disease were determinants for short stature, low weight, or low BMI.

Keywords: Respiratory tract diseases. Respiratory hypersensitivity. Asthma. Growth

1. Universidade de Brasília (UnB)
2. Hospital de Criança de Brasília José Alencar (HCB)

Humanization of care in Pediatric Oncology: impacts of the remodeling of public hospitals interior design in Rio de Janeiro

Carolina Steinhauser Motta[1]
Thaís Jeronimo Vidal[1]

Abstract

Introduction: In Brazil, childhood cancer is the leading cause of death by disease amongst children and adolescents. Given the complexity of the disease, treatment is often multimodal, and it involves long hospital stays. In this context, cancer care presupposes the recognition of social and subjective dimensions, and it is important to value instruments that give new meaning to the intervention and care model. The Desiderata Institute, in conjunction with public health managers, health professionals, and civil society, has carried out, over the last fifteen years, seven humanization of care projects in public hospitals in the state of Rio de Janeiro. The remodeling of hospital spaces aimed to improve the quality of cancer care and reduce pediatric suffering.

Objective: This work aims to share the strategies of remodeling the interior design of public hospitals in Rio de Janeiro that care for children and adolescents with cancer, in order to encourage similar humanization of care practices in other territories.

Method: From 2007 to 2022, the humanization of care process was carried out in five hospitals in Rio de Janeiro and involved six main steps: (1) the Hospital showed interest in the project; (2) formalization of the partnership between the Hospital and the Desiderata Institute; (3) mobilization, by the Institute, of people and companies interested in supporting the project; (4) carrying out, under the responsibility of the Hospital, the necessary civil works; (5) transformation of the space under the coordination of the scenographer and designer team; and (6) evaluation of the impacts of ambience for users, caregivers and health professionals through a public opinion survey with unidentified participants.

Results: The remodeling was carried out in five public hospitals: Hospital Federal dos Servidores do Estado, Instituto de Puericultura e Pediatria Martagão Gesteira, Instituto Estadual de Hematologia (Hemorio), Hospital Federal da Lagoa and Hospital Municipal Jesus. These spaces, which included chemotherapy and diagnostic rooms and pediatric wards, were designed with a seabed inspired scenography. In 2021, 10,528 children and teenagers benefited from this project. The satisfaction survey indicated that the humanization of these spaces reduces pain and anxiety and encourages adherence to treatment. For health professionals, the humanized spaces also improved satisfaction with the work environment, in addition to reduced children's negative reactions to certain invasive procedures. It was also found that there was a decrease (up to 77%) in the need for anesthetics for CT scan.

Conclusion: The experience in Rio de Janeiro has shown that the remodeling of hospital spaces can be a first step towards the humanization of care. Therefore, in the pediatric context, it should be recognized as a strategic action for the implementation of the National Humanization Policy. Rethinking the spatial and esthetic standards of hospitals can promote changes in health production and promotion practices, minimizing the impacts of treatment and making the hospital environment more welcoming and playful for children, adolescents, and their caregivers.

Keyword: Humanization of assistance. Health policy. Oncology service. Hospital pediatrics. Medical oncology.

1. Instituto Desiderata

Immunoglobulin replacement therapy in children: a comparative study in patients with primary and secondary causes of hypogammaglobulinemia

Renata Portella Almeida Grattapaglia[1]
Cláudia França Cavalcante Valente[2]
Fabíola Scancetti Tavares[2]
Camila Teles Machado Pereira[2]
Flaviane Rabelo Siqueira[2]
Laísa Machado Bomfim[2]
Karina Mescouto de Melo[2]

Abstract

Introduction: Hypogammaglobulinemia is defined by IgG serum levels below the age-reference values. It results from an underlying inborn error of immunity (IEI), named Primary Hypogammaglobulinemia (PH) or from secondary causes, such as neoplastic diseases, nephrotic syndrome, or adverse effects to medication, named Secondary Hypogammaglobulinemia (SH). In both cases, when immunoglobulin replacement therapy (IgRT) is indicated, it can reduce infections, morbidity, and mortality.

Objective: To study the clinical and laboratory characteristics of children with PH and SH under regular IgRT, before (pre) and after twelve months (post) initiation of IgRT.

Methods: Descriptive study carried out from March2022 to January 2023, with data collected from medical records of patients with diagnosis of PH and SH. All patients were under regular IgRT, intravenous (IVIG) or subcutaneous (SCIG), in a tertiary pediatric hospital of Brasilia/Brazil. RedCap and Excel softwares were used to store the data. Statistical analyzes were performed using GraphPad Prism® software version 6.0.

Results: Forty-seven patients were studied, 25 with PH (53.2%) and 22 with SH (46.8%). Most patients were male (70.2%). Common Variable Immunodeficiency (n= 7/ 28%) was the predominant diagnosis, followed by Unspecified Hypogammaglobulinemia (n = 6/ 20%), in PH and, Nephrotic Syndrome (n= 14/ 63%) in the SH group. Most patients with PH were under IVIG (n=20/ 80%). In contrast, SCIG was the predominant route in patients with SH (n=18/ 81.8%). We noted a significant increase in mean serum IgG levels in both groups post-IgRT, from 212 mg/dL to 839 mg/dL ($p < 0.0001$) in the PH group, and from 65.5 mg/dL to 578 mg/dL/ ($p < 0.0001$) in the SH group. Unexpectedly, significant increase in mean serum IgA levels in the SH group, from 27.65 mg/dL to 68 mg/dL ($p=0.0009$) was also noted. The total number of infections was significantly reduced post-IgRT in both groups, from 68 to 36 ($p= 0.011$) in the PH group and, from 68 to 34 ($p= 0.015$) in the SH group. The number of severe infections also decreased, from a total of 45 to 4 episodes ($p = 0.0007$) in the PH group, and from 49 to 21 episodes ($p = 0.0263$) in the SH group. In both groups, pneumonia and gastrointestinal tract infection were the most frequent diagnosis pre– and post– IgRT.

Conclusion: Corroborating the literature, our study indicates that, independently from the cause of hypogammaglobulinemia (PH or SH), both groups of patients had clinical and laboratory improvement in their immune response after IgRT.

Keywords: Immunodeficiency. Hypogammaglobulinemia. Immunoglobulin. Pediatrics. Therapy.

1. Universidade Católica de Brasília (UCB)
2. Hospital da Criança de Brasília (HCB)

Impact of omalizumab treatment in children with severe asthma

Vítor de Carvalho Neiva Pinheiro
Cláudia França Cavalcante Valente[1]
Carmen Livia Faria da Silva Martins[1]

Abstract

Introduction: Asthma is a disease characterized by chronic inflammation of the airways, defined by the presence of respiratory symptoms such as wheezing, shortness of breath, chest tightness and cough that vary over time and in intensity, associated with variation in expiratory flow limitation. Allergic asthma is the most easily recognized phenotype, usually starting in childhood, and associated with a personal or family history of allergic diseases, such as eczema, allergic rhinitis, and allergy to food or medication. Omalizumab is an anti-IgE monoclonal antibody that conjugates all forms of free circulating IgE, leading to the inhibition of IgE-dependent processes such as antigen presentation, mast cell and basophil degranulation, and eosinophilic infiltration. Eligibility criteria for its use include the number of exacerbations in the previous year, allergen sensitization, total serum IgE level, and patient weight. Treatment with omalizumab in patients with severe asthma has shown good results in randomized clinical trials and real-life studies conducted outside Brazil, but there are still few studies conducted in Brazil.

Objectives: The primary objective of this study was to evaluate the use of omalizumab in the treatment of severe asthma in children and adolescents followed up at a tertiary reference service of the Unified Health System (SUS) in Brasília, based on the reduction in the incidence of exacerbations, the improvement in symptoms between exacerbations and in lung function, in addition to reducing the use of inhaled corticosteroids. The specific objectives were to compare scores on the Pediatric Asthma Quality of Life Questionnaire (PAQLQ) and the Asthma Control Test (ACT) spirometry, the number of exacerbations and hospitalizations due to asthma, the daily dose of inhaled corticosteroids before and during treatment with omalizumab.

Methods: This is a longitudinal descriptive and analytical study, with a retrospective and prospective design, in patients between 6 and 18 years of age diagnosed with severe asthma, treated at a tertiary pediatric hospital. The indicators evaluated were daily dose of inhaled corticosteroid (IC), scores on the Asthma Control Test (ACT) and Pediatric Asthma Quality of Life Questionnaire (PAQLQ) spirometry, number of attacks and annual hospitalizations due to asthma.

Results: 14 patients were included in the study. There was a significant reduction between the initial dose of IC and the doses at 9 and 12 months of treatment ($P<0.01$). There was a significant increase in ACT ($P=0.001$) and PAQLQ ($P=0.003$) scores. The annual number of asthma attacks showed a significant reduction ($P=0.001$), as well as the number of hospitalizations ($P=0.041$). Spirometry did not show significant variation. There were no adverse reactions in the evaluated patients.

Conclusion: Patients treated with omalizumab had a significant reduction in the daily dose of IC, number of attacks and annual hospitalizations due to asthma, and a significant increase in the asthma control indicators (ACT and PAQLQ). It is important that more studies about immunobiological treatments are carried out within the social and economic context of Brazil and other developing countries.

Keywords: Asthma. Omablizumab. Monoclonal antibodies. Immunoglobulin E.

1. Hospital da Criança de Brasília (HCB)

Impact of type of labor in the establishment of breastfeeding during the first hour of life: a cross-sectional observational study

Bianca de Carvalho Nóbrega[1]
Lívia Beatriz Teobaldo de Oliveira

Abstract

Introduction: Maternal milk is primordial for the baby's physical and emotional development, as wee as benefiting the mother`s health. Even more crucial is breastfeeding during the first hour after delivery. The efficiency of hospital intervention in promoting breastfeeding depends particularly on the identification of mothers with increased risk of not starting or early interrupting lactation. This risk is associated, amongst other factors, with the labor type, particularly C-sections. In this respect, the increasing evidence suggests that the Child-Friendly Hospital Initiative from UNICEF, with its initiatives to protect, promote and support breastfeeding, is associated with the growth of the beginning, duration, and exclusivity of breastfeeding.

Objectives: To compare the statistic difference of breastfeeding difficulty in the first hour after labor, among normal birth and C-Section postpartum women, in a Child-Friendly Hospital.

Methods: A cross-sectional study with 300 puerperal women in the Brasilia Maternal Infant Hospital joint accommodations, previously approved by the Research and Ethics Committee and containing the Term of Freed and Clarified Consent signatures, in accordance with the standards established by the CONEP 466/ 2012 and 510/ 2016 resolutions, number of Approval Opinion 5.034.034. The collected data through interviews and medical records was analyzed through the Odds Ratio statistical test, considering as variables: ´labor type´, ´breastfeeding difficulty´ and ´moment of breastfeeding onset´.

Results: The Odds Ratio comparing labor type with breastfeeding difficulty in the first hour after delivery shows 1,6 C-Section postpartum women with breastfeeding issues for each normal birth postpartum women with breastfeeding issues. Despite that, the Forest Plot graphic goes beyond the non-difference line, which indicates statistical insignificance. Hence, there is a statistical possibility that there is no difference in the breastfeeding difficulty rate in the first hour after birth, when comparing labor types. In contrast, the Odds Ratio that analyzes the influence of moment of breastfeeding onset with the presence or absence of difficulties, regardless of labor type, exposes that there are 0,26 postpartum women with breastfeeding issues in the first hour after labor for each postpartum women with difficulty that started breastfeeding only after the first hour. Therefore, there is an almost five times bigger chance of difficulties in breastfeeding when its onset is delayed. Besides, it's noticeable that 54% of delaying breastfeeding motives after C-Section are related to the duration of the surgical labor procedure, even in the absence of unexpected events.

Conclusion: The hypothesis that labor type impacts on the breastfeeding success is refuted due to statistical insignificance. Meanwhile, it's remarkable that the protective factors for the establishment and success in breastfeeding are I) early onset, during the so called ´golden hour´, and II) breastfeeding support through humanizing strategies and institutional care technologies, represented by the Child-Friendly Hospital Initiative. In addition, the perception that the cesarean procedure itself acts as a risk factor for breastfeeding makes the implementation of hospital strategies focused on mitigation of the C-section challenges essential for successful breastfeeding.

Keywords: Breastfeeding. Cesarean section. Perinatal care. Natural childbirth. Quality indicators. Healthcare.

1. Escola Superior de Ciências da Saúde (ESCS)

Impacts of facilitating access to health services among children with cerebral palsy in socially vulnerable circumstances

Thamiris da Silva dos Santos[1]
Nadine Oliveira Cabral
Júlia Araújo Goulart
Nayara Cristina de Jesus Silva
Ranny Keatlyn de Oliveira
Kennea Martins Ayupe
Aline Martins de Toledo

Abstract

Introduction: Cerebral Palsy (CP) is a neurological condition that presents permanent motor and cognitive disorders, and consequently, can cause some levels of disability. Access to health services influences the quality of life of children with CP, since, if limited, it can restrict access to care, interventions, and auxiliary technologies. In this sense, the extension project Care for CP (*'Cuidar de PC') from* the University of Brasilia, seeks to facilitate the access of children with CP and their families to these services. Furthermore, the project acts as an itinerant tool, establishing a connection within a multi-professional network composed of doctors, occupational therapists, and physical therapists. In addition, it facilitates partnerships with professionals who manufacture low-cost auxiliary technologies, such as PVC walkers and parapodiums, economically more accessible to families exposed to vulnerability.

Objectives: To observe the influence of the "Care for PC" extension on access to health services in children with CP subject to social vulnerability in the Federal District.

Methods: This is an observational and documentary study, based on experiences and data provided by the extension project "Follow-up and Therapeutic Planning of Children with Cerebral Palsy: Caring for CP, hosted by the Universidade de Brasília, which currently serves 34 children with the condition of cerebral palsy. The selected variables were taken from records in the project database, and they were related to access to health services, social and economic factors.

Results: It was observed that assisted children are four times more likely to use the Unified Health System (SUS), which is the public health system in Brazil, than to obtain a health insurance plan. As a result, 29.4% undergo physiotherapeutic treatment through the SUS or philanthropic clinics. It is estimated that, on average, six out of ten families with members with CP do not have formal or fixed income. Of the thirty-four children, 38.2% had easy access to low-cost technologies, such as a walker made of PVC. Approximately 11.7% received gaiters, offered free of charge by the project, and 17.6% had lower limb orthoses with the discount offered by partnerships with the Care for CP initiative. About 23.5% were referred to physiotherapy, 14.7% to occupational therapy and 20.5% had botulinum toxin (TBA) application made possible.

Conclusion: Children admitted by the project had easy access to consultations, instruments, clinics, orthotics, and walkers. Such access can provide benefits such as independence, accessible technologies, improved quality of life and the possibility of a multidisciplinary follow-up. The study points to the extreme importance of the initiative and role of Caring for PC in society, health policies, referrals, and promotion of quality of life.

Keywords: Cerebral palsy. Health services accessibility. Healthcare policies. Health-related quality of life.

1. Universidade de Brasília (UnB)

Impacts of sexual violence on learning in adolescents

Vinícius dos Santos Silva Mohn[1]

Abstract

Introduction: Adolescence is a period that involves the most profound changes, namely biological, psychological, social, and behavioral. Sexual Violence (SV) is any sexual act attempted or consummated without the victim's consent, exercised by coercive or intimidating means, with the use of physical force, threat, weapons, or psychological fear, according to the World Health Organization. SV statistics against adolescents, despite numerous published works, are still difficult to access and, therefore, inconclusive, affecting the consistency of these data. Violence has a wide range of consequences ranging from physical to psychological, behavioral, cognitive, and social, including learning difficulties, which can lead to loss of the motivation to acquire knowledge, difficulty in attention and socialization. The experience of the trauma of having suffered SV influences the learning processes and the future social being.

Objective: To analyze the impact of sexual violence on learning among adolescents in the reference service.

Methods: Observational, descriptive, and cross-sectional study. Data were stored in a Microsoft Excel database and analyzed using SAS Enterprise Guide 5.1. The project was submitted to the ethics and research committee and approved under number CAAE: 92506618.0.0000.8027 and 92506618.0.3001.5553.

Results: Of the total of 90 adolescents evaluated, 84.44% of the victims are women and 75.56% of the victims identify themselves as brown. The average age of females is 13.80 years and 12.64 years for males. Ninety percent of the aggressors were known to the victims and 97.77% were male. Regarding the victims' schooling, comparisons reveal that most adolescents had low school performance caused by concentration and learning difficulties (62.2%). 26.7% had an unjustified drop in school attendance. 39.53% of the victims are behind in relation to their school age. The average delay is 2 school years.

Conclusion: The impacts of violence on learning are a reality, the findings reflect low school performance due to difficulty in concentrating and, consequently, learning difficulties. The delay in the age/grade ratio causes not only academic damage, but also social and self-esteem damage, as they live with the discrepancy of their age in relation to their peers and may even be a risk factor for other types of violence, such as bullying.

Keywords: Adolescence. Sexual violence. Learning disability**.**

1. Universidade Católica de Brasília (UCB)

Induction treatment in children with acute lymphoblastic leukemia (ALL): assessment of compliance with the proposed protocol and complications.

Ana Clara Pellizzaro da Motta[1]
Ciro Moisés Oliveira Vieira dos Santos
Estefânia Rodrigues Biojone[2]

Abstract

Introduction: Induction, the initial phase of ALL treatment, is crucial for the clinical outcome. Assessment of Minimal Residual Disease at the end of induction is the main prognostic factor in ALL. In addition, the rates of complications and mortality in this period are quality indicators of the oncology services. Several studies have evaluated complications and mortality during the induction phase, however data regarding failures or delays in the administration of chemotherapy are scarce.

Objectives: Evaluate compliance with the proposed chemotherapy treatment during the induction of children with ALL B, identify reasons for non-compliance with the planned protocol, and describe the complications presented.

Methods: Retrospective study with children between 1 and 18 years of age, undergoing treatment for ALL B at the Hospital da Criança de Brasília (HCB) from July 2018 to December 2019. Data (doses and dates) were collected regarding prescriptions of chemotherapy drugs used in the stages 1 and 2 of induction. Complications presented during the induction phase were evaluated.

Results: 40 children received induction treatment for ALL B with a therapeutic scheme based on the BFM 2009 protocol. Thirty patients (75%) were classified as intermediate risk, 9 as high risk and 1 patient as low risk. One patient died during induction D24 (2.5%). Of the 39 patients who completed induction, all received the four predicted doses of Vincristine, with administration delayed in one case due to infection. Furthermore, Daunorubicin was administrated in accordance with the time and dosage provided by the protocol, in 29 (74%) patients. The causes for modifying the anthracycline were infection (2 patients), national shortage of the drug (replacement by another anthracycline, 7 patients). However, in one patient daunorubicin was replaced by doxorubicin with no described justification. All patients received PEG asparaginase (1 to 2 doses from 1000mg/m² to 2500mg/m²). Of the 39 patients who completed the first induction phase, 4 proceeded to the intensification blocks (HR). Two patients had no record of CT in phase 2 of the induction. Thirty-three patients who received phase 2 of induction were analyzed, of which only 6 (18%) received chemotherapy drugs within the expected time. In 27 patients, there was some delay in the administration of cyclophosphamide or SC cytarabine. Also, the main causes of temporary discontinuation of chemotherapy were hematological toxicity (58%) and infections (with neutropenia) (44%). As a result, infection was the most frequent complication (15 patients, 62%), with admission to the intensive care unit in three cases (7.5%).

Conclusion: As described, we observed that infectious complications and hematological toxicity often prevent the completion of the protocol within the expected time. Our data suggests the possibility of adopting less intensive protocols, especially in the second phase of induction, aiming to reduce interruptions in treatment. It is important to evaluate the association between minor interruptions in chemotherapy treatment and the clinical outcome after induction. This study is being expanded.

Keywords: Acute Lymphoblastic Leukemia. Chemotherapy. Induction. Complications.

1. Centro Universitário de Brasília (CEUB)

2. Hospital da Criança de Brasília José Alencar (HCB)

Influence of Social Determinants of Health for children with Cerebral Palsy in the Federal District

Ranny Keatlyn de Oliveira[1]
Aline Martins de Toledo
Nadine Oliveira Cabral
Nayara Cristina de Jesus Silva
Taís Petrucci Boechat
Sthefany da Silva Souza
Kennea Martins Ayupe

Abstract

Introduction: Taking care of a child with Cerebral Palsy (CP) can have physical and mental impact on the health of their caregivers/guardians. One of the main challenges is managing the problems and demands of the child's daily life. In addition, there is a notorious interference related to the Social Determinants of Health (SDH), which are characterized by the conditions of life and work, through which the impacts resulting from the level of education, occupation of the main responsible person, family income, and access to social benefits can be observed.

Objective: To analyze the influence of SDH on children with CP in the Federal District (DF).

Methods: Cross-sectional study, with an epidemiological profile, carried out with children with CP of all clinical types and Gross Motor Function Classification System (GMFCS) levels, residing in the DF, aged 0 to 17 years (CAEE: 28540620.6.1001.5133). The variables analyzed were socioeconomic aspects of the main caregivers, access to health services and level of education. Statistical analysis was performed using the Statistical Package for Social Sciences software, version 20.0, using descriptive analysis, presenting means, medians, and standard deviation with a confidence interval of 95% and significance value of P ≤0.05.

Results: The sample consisted of 51 children with a mean age of 5.8 years (±0,829), predominantly at level III of the GMFCS classification and most classified as spastic-type CP. As for the main caregiver, it was observed that the majority (35.3%) have completed merely high school, which can directly influence the source of family income, justifying the fact that 60.8% of those responsible do not have a stable source of income and 37.3% do not have an occupational activity outside the home environment. Such instability affects the total family income, which remained at an average of 1.5 minimum wages (R$ 1,941.00) in families with 3 to 4 components, leading to unfavorable socioeconomic conditions. It is worth mentioning that the Continuing Provision Benefit (BPC) helped to compose 56,9% of family income, proving to be an indispensable value for the economic maintenance of the family. Socioeconomic vulnerability directly reflects on adherence to public health through the Unified Health System (SUS), so most children depend on this system, which provides an insufficient number of services to fully attend to children's needs. These gaps can be observed, for example, concerning physical therapy intervention, to which 49% of children do not have access.

Conclusion: From the results obtained, the importance of investing in Public Policies in the family context of children with CP is observed. Investments are needed in health education for the families and in access to health services that address the specific demands of each child, given that these directly compromise family income and, consequently, the family's quality of life.

Keywords: Cerebral palsy. Health social determinant. Public policies.

1. Universidade de Brasília (UnB)

Interactional experiences of the child in oncological living: identified strategies for coping and support.

Dhiovanna Evelynn Santos Tavares[1]
Aline Oliveira Silveira
Camila Dornelas de Carvalho e Garófalo

Abstract

Introduction: Childhood cancer is a life-threatening disease that brings profound and permanent changes in the life of the child and the family. Bone Marrow Transplantation (BMT) is nowadays one of the most favorable treatments for the prophylaxis of onco-hematological diseases. However, BMT is characterized as an aggressive and complex procedure, subject to adverse effects like any other procedure, so for the patient it is even more stressful, long and permeated by losses of all kinds.

Objective: To describe the experience of children and adolescents with cancer undergoing bone marrow transplantation, in the management of living with cancer, and the support perceived in the relationship with family, with oneself, and with health professionals.

Methods: Descriptive, cross-sectional study with a qualitative approach and supported by the theoretical framework of Symbolic Interactionism (SI). Data were collected by means of in-depth audio-recorded interviews. Participants: children and adolescents between 6 and 18 years old who underwent Bone Marrow Transplantation (BMT) and were being followed-up after the transplantation in the institution elected as the study site.

Data analysis: Narrative analysis from a holistic perspective with emphasis on content, supported by the theoretical framework of Symbolic Interactionism.

Results: Three adolescents and four children in post Bone Marrow Transplantation (BMT) participated in the study. The content of the children's and adolescents' narratives were grouped into 4 thematic categories: interactions with professionals, interactions with family and significant support network, the role of playing and recreation, interactions with oneself. In general, children in oncological treatment and bone marrow transplant define this experience as challenging and life transforming, thus, they define and re-signify living with cancer in the interactions established with family, friends, themselves through internal resources, and with health professionals among other people who are part of their support network and share the trajectory of diagnosis and treatment. In the trajectory of living with cancer treatment, the child interacts with the disease, with the transplant, with family and friends, with health professionals and with themselves, towards their own self. They internalize symbols, define and act in the present situation, and project expectations for the future. The continuity of affective relationships is crucial for the acceptance and good development of the treatment. What follows from this can be seen as a dimension of nursing care.

Conclusion: In this study it was found that children and adolescents with cancer after Bone Marrow Transplantation (BMT) find management strategies in affective relationships, in play, and in themselves, creating internal mechanisms for coping and developing hopeful resources. This study identifies important elements that can support future research questions, relating coping strategies, hope and individual and family resilience.

Keywords: Children. Adolescents. Bone marrow transplantation. Cancer.

1. Universidade de Brasília (UnB)

Medulloblastoma correlation of radiological images at diagnosis with histological and molecular subtypes of a single-center patient cohort

Emanoelle Cristina Machado da Silva[1]
Flávia Delgado Martins[2]
Bruna Arrais Dias
Diógenes Diego de Carvalho Bispo[2]

Abstract

Introduction: Currently, medulloblastoma is classified into four molecular subgroups, with distinct genomic, epidemiological, and prognostic characteristics: Wingless (WNT), Sonic hedgehog (SHH), Group 3 and Group 4. This genotypic classification allows a more individualized therapeutic planning according to risk stratification, with consequent benefit to patients' outcomes.

Objective: Correlate the heterogeneous aspects of magnetic resonance images with the histological and molecular characteristics of this tumor.

Method: Medical records, pre-surgical radiological images and the histological and molecular classification of all patients aged less than 18 years with medulloblastoma, treated at the children's oncology reference institution between 2011 and 2021, were analyzed. The images were evaluated by an experienced neuroradiologist in the area, blinded to clinical and molecular information.

Results: Of the 47 patients with medulloblastoma, 32 met the study eligibility criteria and were analyzed after the biomolecular and radiological study. The mean age at diagnosis was 7.2 years. 23 patients were male, 8 presented metastasis at diagnosis, and 7 had partial resection. Analysis of diagnostic images revealed tumor location, presence of hemorrhage/calcification, tumor margins and enhancement pattern as predictors in identifying molecular subgroups. It was observed that the SHH subgroup had a significantly more common location in the cerebellar hemisphere, less presence of hemorrhage/calcification and ill-defined tumor margins compared to the other subgroups. Group 4 showed significantly less enhancement compared to the other subtypes. In the diffusion restriction analysis, it was observed that the values of the tumor-thalami ratio and the ROI of the whole tumor were significantly higher for the WNT subgroup in relation to the others.

Conclusion: Despite the limitations, it was possible to identify characteristics that may contribute to the use of magnetic resonance as a method of individualizing the approach to patients with medulloblastoma. The characteristics identified by the radiological analysis of the tumors that can predict the molecular subgroup can certainly contribute to a better therapeutic approach, with consequent lower incidence of post-surgical sequelae. The diffusion study must be better characterized before its use in clinical practice, although it seems to provide relevant data for the imaging diagnosis of medulloblastoma subgroups, being a promising analysis.

Keywords: Central nervous system neoplasms. Classification. Pediatrics. Magnetic resonance imaging.

1. Universidade Católica de Brasília (UCB)
2. Hospital da Criança de Brasília José Alencar (HCB)

Minimal residual disease detection using allele specific PCR (AS-PCR) in ML-DS patients

Brenno Martins Henrique[1]
Ricardo Santos Camargo[2]
Agenor de Castro Moreira Júnior[2]
Marina da Costa Ribeiro[2]
José Carlos Martins Córdoba[2]
Isis Maria Quezado Magalhães[2]

Abstract

Introduction: Children with down syndrome are more likely to develop hematological malignancies, and in some cases, patients may develop a rare and specific myeloid leukemia (ML-DS). In addition to other biological events, trisomy of chromosome 21 alongside with mutations on exons 2 and 3 of the hematopoietic transcription factor GATA-1 triggers abnormal cellular proliferation. GATA-1 mutations are known to disturb the abundance of full length GATA-1 protein, leading to elevated expression level of a truncated isoform (GATA1s). Although these mutations are more likely to occur on exons 2 and 3, they can appear in different ways, including substitutions, duplications or deletions. Thus, these molecular alterations can be used as molecular targets to identify malignant cells in the diagnosis or disease relapses. In this work we take advantage of this molecular landscape, based on specific mutation detection, to monitor patients diagnosed with ML-DS who were submitted to therapeutic scheme.

Objective: Use GATA1 allele specific PCR to detect minimal residual disease in patients previously diagnosed with ML-DS.

Methods: Patients who had previous clinical and laboratory diagnosis to ML-DS were selected. GATA1 mutation in each sample was assessed by Sanger sequencing (3500 Series Genetic Analyzer). Based on the mutation identified in each sample, oligonucleotides were designed to specifically detect these mutants. After conclusion of pharmacological treatment, minimal residual disease was assessed by both mutations specific PCR and flow cytometry (BD FACSCanto™

Results: Laboratory diagnosis was performed initially trough flow cytometry analysis. Selected patients who presented blood blasts compatible with ML-SD were submitted to DNA sequencing analysis that revealed the presence of mutations located on exons 2 and/or 3 of gene GATA1. Primer design for allele specific PCR was conducted, seeking to present a mismatch in the 3rd nucleotide from the 3'end. This strategy led to a high specificity amplification. Allele specific PCR amplification was conducted alongside flow cytometry to detect minimal residual disease. As a result, assessing minimal residual disease status through detection of GATA1 mutations by AS-PCR presented a higher sensitivity than flow cytometry antigen detection.

Conclusion: Understand the molecular landscape of each kind of tumor is a key step to personalized treatment and care. Mutation specific PCR is a sensitive and effective technique that can assist on minimal residual disease detection and thus cooperate in clinical decision-making processes. Moreover, the strategy presented here represents a personalized and target-based scheme for patient care.

Keywords: Myeloid leukemia. Down syndrome. PCR. Minimal residual disease.

1. Universidade de Brasília (UnB)

2. Hospital da Criança de Brasília José Alencar (HCB)

Protective factors for the health of children under six months of age during the pandemic period

Gabriela Gomes Espindola[1]
Gabriela Dominicci de Melo Casacio
Katherine Slowinski Knapp
Adriana Zilly
Andrea Ferreira Ouchi França
Rosane Meire Munhak da Silva

Abstract

Introduction: The Ministry of Health advises actions like immunization, breastfeeding, growth and development monitoring, and disease control to improve and protect child health. Therefore, identifying and guaranteeing those health-protective factors is relevant and can reduce infant morbimortality.

Objective: To describe protective factors for the health of children under six months during the Covid-19 pandemic.

Method: Descriptive research, with qualitative approach, developed in seven cities of Foz do Iguaçu regional health department, between May and December of 2022, through a survey carried out in person or remotely, using a structured instrument. The study included mothers aged 18 years old or over, with children under six months, born in a maternity that belongs to the above-mentioned regional health department. Mothers with clinical or mental health problems that prevented the instrument application were to be excluded, but that did not happen. This study is from a multidisciplinary project entitled 'Fight against COVID-19 and maternal and child health', approved by the Human Subjects Ethics Committee of State University of Western Paraná, under record number 4.837.617.

Results: From 118 participants, children who attended five or more childcare appointments presented less need for acute conditions care and hospitalization. Of these, 4.2% needed urgent care, and 8.5% got hospitalized. Regarding the exclusive breastfeeding period, 70.3% of the children were breastfed for 90-180 days while 29.7% were breastfed for 0-90 days. Exclusive breastfeeding until six months is one of the main recommendations for integrated management of childhood illness because it is a protective factor since it enhances the immune system. Of those children breastfed for 0-90 days, 17.1% required urgent care and 22.9% hospitalization. Although telehealth was an alternative during the pandemic, only 11.9% of the children received this care modality, and 7.1% got hospitalized. The reasons that led to urgent care were respiratory problems (63%), jaundice (13%), difficulty in weight gain (5.6%), and allergic problems (3.8%). Hospitalization included respiratory problems (34.8%), jaundice (21.7%), asphyxia (8.7%), and fever (8.7%). The results relate to another study in which respiratory problems are one of the main factors in infant morbimortality.

Conclusion: The research indicates that exclusive breastfeeding, childcare appointments, and telehealth were protective measures for children's health during the pandemic. However, other strategies are required to guarantee comprehensive healthcare for children.

Keywords: Childcare. Pediatric nursing. Hospitalization.

1. Universidade Estadual do Oeste do Paraná (UNIOESTE)

Rare diseases, social interface, and access to food: journeys of mothers who care for children with rare complex chronic conditions

Daniela Amado Rabelo[1]

Abstract

Introduction: This is a real-world everyday life research based on the narrative illnesses of mothers caring for children with Inborn Error of Metabolism (IEM), Classical Homocystinuria (HCU). IEMs are chronic, complex, and rare conditions that can develop from childhood to adulthood and affect the entire family system in singular physical, psychological, and social ways. HCU prevents the metabolism of the amino acid methionine, due to the deficiency of the enzyme cystathionine beta-synthase, which catalyzes the conversion of homocysteine into cystathionine. When untreated, it can present outcomes such as severe ocular changes, cardiovascular and vascular diseases, intellectual disability and even death.

Objectives: To present the social interface in the routine of mothers who care for children with Classical Homocystinuria, based on social health determinants that impact access to food for their children.

Methods: Exploratory, comprehensive, and qualitative study of the daily life of five mothers who take care of children between 03 and 12 years old, with IEM. The study had a national dimension with expected saturation in data collection. It used semi-structured interviews, application of sociodemographic forms, non-participant observation in community events and analysis of non-scientific documents. There was use of instrument validation and a research diary and memos after the interviews. Data integration was carried out with Conversation Analysis on the premise that social interaction is built by alternating roles through successive verbal and non-verbal actions with observation of the researcher in their interactions in the field.

Results: The sociodemographic profile indicates an individual, social, economic, and informational vulnerability in the context of traffic life and access to treatment for their children. Mothers have different educational levels, and, in most cases, low socioeconomic conditions (60%), and lack of social benefits for the treatment. There is access to the metabolic formula by the majority, but intermittently or seasonally, in shortages and through bureaucratic procedures. There is no offer of special food by the State, with high costs of freight for people who live far from the capitals. Mothers need to move between 19 settings, which range from the space of micro-relational exchanges to macrosystems, external to the family nucleus. There are three turning points in the DR event, two of them negative (diagnosis and relearning to eat) and one positive, in the organic solidarity of the association and its leader, with emphasis on the formation of an affective-info-communicational support network, mediation of care in accessing food and the multidisciplinary network for care.

Conclusion: The challenges make mothers vulnerable in three overlapping dimensions (as persons, women, and mothers). Their life contexts, in terms of social determinants of health, are allied to a vulnerability to a rare disease. The solution is mediated by associations, in organic solidarity in bio sociability. The group exerts info-communication interoperability even in the presence of loss of autonomy, increased vulnerabilities and stigma, discrimination and social exclusion experienced in everyday life.

Keywords: Rare diseases. Metabolism. Inborn errors. Homocystinuria mothers. Social determinants of health.

1. Universidade de Brasília (UnB)

Relationship between levels of participation and desire for change in primary caregivers of children with cerebral palsy

Ranny Keatlyn de Oliveira[1]
Nadine Oliveira Cabral
Ana Priscila da Silva Teixeira
Taís Petrucci Boechat
Júlia Araújo Goulart
Egmar Longo
Aline Martins de Toledo

Abstract

Introduction: Cerebral Palsy (CP) is the most common physical disability in childhood and results in injuries that predominantly lead to movement disorders, whether simple or complex. The clinical characteristics are diverse, emphasizing difficulties in locomotion, speech, and manipulation of objects, which directly affect participation of those who present this condition. Children with disabilities often do not have the same opportunities as their peers, so it is common to observe, in family members and guardians of children with CP, the desire for them to become more involved in daily activities, and to participate in a greater variety of activities.

Objective: To verify correlations between the frequency of participation of children with CP in activities at home, at school and in the community, and the existence of a desire to change the level of participation of children by those responsible.

Methods: Preliminary cross-sectional study, which is part of a multicenter longitudinal study approved by the Ethics Committee (CAAE: 28540620.6.2005.8093). The sample included 51 children with CP, aged 5 to 10 years, residents of the Federal District, of all levels of Gross Motor Function Classification (GMFCS) and Manual Ability Classification System (MACS). The Participation & Environment Measure Children and Youth version (PEMCY), completed by the primary caregiver, was used to assess the level of participation of children and the presence of a desire for change on the part of those responsible for them. The variables were analyzed using descriptive statistics, using means, medians, and standard deviations. The level of correlation was analyzed using the Spearman test. For all analyses, the significance of a per value lower than 0.05 ($p<0.05$) and a Confidence Interval (CI) of 95% were adopted.

Results: Ten children with CP were evaluated, with a mean age of 8.17 years (± 1.01). The predominant GMFCS and MACS classification levels in the sample were II, in both cases. The data collected through the PEMCY instrument revealed that the sample performs 52.5% (± 0.76) of daily activities frequently, which includes household chores, games, and school and community activities. The desire to change the level of participation in activities carried out at home, at school and in the community, on the part of those responsible for the children, was present in 62%, 58% and 68% of the cases, respectively. There was a significant, strong and negative correlation between the frequency with which children with CP perform activities at home and the parent's desire to change activities both at home and at the school or in the community ($r [10] = –0.831$, $p<0.001$).

Conclusion: A negative correlation was found between the desire for change expressed by the main caregivers in all environments analyzed, and the frequency of activities that children perform at home. This allows us to infer that the greater the frequency of child participation in the tasks at home, less is the interest shown by caregivers for changes in the child's general behavior.

Keywords: Cerebral palsy. Social participation goals. Daily living activities.

1. Universidade de Brasília (UnB)

Simulation team training: experience in a pediatric hospital coping with COVID-19

Fernanda Cunha Azevedo[1]
Deivson Mundim[1]
Heloisa Gabriel[1]
Valdenize Tiziani[1]

Abstract

Introduction: The pandemic caused by SARS-CoV-2 virus required interventions to ensure continuity of care processes and reduction of inherent risks in the field of healthcare, guaranteeing patient and professional safety. There were many challenges, especially due to little scientific evidence. It was necessary to identify strategies that would allow collective learning, consolidating a new way of understanding, diagnosing, and solving problems. Based on this scenario, educational actions were structured aiming to support the adoption of safe techniques and work processes for coping.

Objective: To report experiences of qualifying care teams in the pandemic context, with practices based on the simulation methodology, enabling assessment of vulnerabilities and adjustments of care flowcharts for emergency scenarios.

Method: 7 simulations were carried out over 6 months, namely: care flowchart for suspected Covid-19 patients in the ICU (n=1), transfer flowchart of the patient with Covid-19 from the ICU for a surgical procedure (n=2), flowchart of death of the patient with Covid-19, and communication of bad news in the ICU (n=2), death management flow in hospitalizations (n=2). The scenarios included an actress, assistance professionals and a team of evaluators (area managers). Each intervention was qualitatively evaluated after completion, using Net Promoter Score – NPS, and in relation to the perception of those involved (reaction evaluation), using a questionnaire with a Likert scale.

Results: 48 professionals participated in the simulations, involving a multidisciplinary care team, hygiene teams, security guards and ambulance drivers. Of these, 52.08% (n=25/48) of the professionals involved answered the applied questionnaires. 86.77% of the respondents totally agreed that the doubts were resolved, 88.10% felt safer in decision making after support offered, 90.21% were able to understand moment and proper use of Individual Protection Equipment, 95.24% reflected on vulnerabilities of the flowcharts, 78.57% resolved doubts about triggering the flowcharts, 74.87% strongly agreed that on-site actions were effective. The NPS was 9.26. DISCUSSION: The Realistic Simulation was chosen because it favors: 1) hands on work, without the risks normally associated with assistance, 2) situational diagnosis and identification of vulnerabilities by managers and teams regarding new flowcharts, and 3) critical reflection and opportune interventions, in line with what the debriefing recommends. It was possible to corroborate these assumptions with collected data when observing the positive impact provided by the participants 'experiences in the simulations. Professionals reported feelings of personal and professional satisfaction, difficulty dealing with emotions and opportunities to be worked on. Use of the methodology for other training courses at the institution was suggested, in addition to new topics.

Conclusion: The experience made it possible to consolidate simulation as a teaching tool capable of motivating and mobilizing employees, stimulating interest in similar actions, opening new precedents. It also allowed for the development of personalized actions aligned with the needs of different areas, using the methodology for crisis management and problem solving. The actions allowed for the improvement of flowcharts established for the pandemic, endorsing, and strengthening decision-making in a little-known scenario.

Keyword: Simulation training. Education. Medical. Healthcare team.

1. Hospital da Criança de Brasília José Alencar (HCB)

Spirometric analysis in pediatric patients with asthma

Giovanna Costa Moura Velho[1]
Marilusa Elisabete Fin[2]
Carmen Lívia Faria da Silva Martins[2]

Abstract

Introduction: Asthma is characterized by chronic inflammation of the airways and is the most common respiratory disease during childhood. The diagnosis is essentially clinical, but spirometry may help in cases of doubt and in monitoring patient evolution, since it verifies whether the treatment is being effective beyond the clinical symptoms. The analysis of spirometric flows in patients with asthma is a crucial study, as it identifies the most frequent types of ventilatory disorders, whether there was a response to the bronchodilator (BD), and the most important flows to be analyzed in the examination according to the age group.

Objective: To characterize the ventilatory disorders of children and adolescents diagnosed with asthma through spirometry.

Method: This is a descriptive, observational, and cross-sectional study using secondary data. All patients were identified by a number to maintain the confidentiality of information, and a term of consent for the participation of children and adolescents was offered to those responsible for them. The research was approved by the Ethics and Research Committee at Plataforma Brasil and at the Hospital where it was carried out. Spirometries performed between January 2015 and June 2019 in patients aged 3-18 years who already had a clinical diagnosis of asthma were included. Exams in which the execution technique failed were excluded. Obstructive ventilatory disorder (OVD) was diagnosed by means of forced expiratory volume in one second (FEV1) < 80% and/or FEV/FVC < 80% and forced mid-expiratory flow (FEF25-75%) < 70%. Furthermore, the OVD was classified as mild, moderate and severe. Response to BD was identified was as: 12% variation in pre– and post-BD FEV1 and/or 200ml in pre– and post-BD FEV1 and/or variation greater than 7% of the predicted value (this criterion only for children over 12 years of age).

Results: 608 spirometries were evaluated and 587 were included in the study. Approximately half of them had OVD, with a percentage of 40% at the expense of FEF25-75% < 70%, with other normal flows. This analysis demonstrated the importance of this spirometric flow in the pediatric population in the diagnosis of OVD. The response to BD was identified only in 23% of the exams, in contrast to the clinical diagnosis of asthma in all patients. This data may suggest greater asthma control in patients who are followed up at this hospital. In addition, the mean age of the patients was 8.68 years, with the youngest being 3 years old. This result shows that very young children can perform the spirometry technique, as long as it is instructed by a well-prepared professional, which demonstrates the importance of the multidisciplinary team in patient care.

Conclusion: The outcome contributed to add data on the epidemiology of one of the most prevalent respiratory diseases in Brazil. In addition, it ratified that the FEF25-75% parameter should always be evaluated in the pediatric population to avoid under-diagnoses and demonstrated the relevance of a multidisciplinary team trained to enable the effective performance of so many tests.

Keywords: Asthma. Respiratory function tests. Spirometry. Pediatrics.

1. Centro Universitário de Brasília (CEUB)
2. Hospital da Criança de Brasília José Alencar (HCB)

The high cost of genetic therapy: a literature review of the impacts in the treatment of spinal muscular atrophy

Natália Martins de Oliveira[1]
Adria Maria Nascimento Junior
Anna Carolina Teixeira Lengruber Amaral
Heloiza Arantes Silva
Mario Augusto Rego de Macedo
Priscila Moreira Mesquita

Abstract

Introduction: Spinal Muscular Atrophy (SMA) is a progressive disease that affects motor neurons, which results in failure to achieve motor milestones. Until 2016, there was no treatment for SMA, but nowadays there are two well-known genetic therapies: Nusinersen (Spinraza®) and Onasemnogene Abeparvovec (Zolgensma®) that have a high success rate. Their action mechanism slows down the loss of functional motor neurons and stabilizes the disease, by promoting the Survival Motor Neuron (SMN) protein expression, improving a better life quality by allowing patients to sit and walk. However, they are the most expensive drugs in history, which raises concerns about population accessibility and the long-term effects.

Objective: This article intends to analyze the high-cost impact of genetic therapy and the current medications in the treatment of SMA related to the cost-benefit of each treatment.

Method: This study was based on an integrative review of literature, with data collected in 9 articles, from the last 6 years, using the databases SciELO and PubMed, with DeCS's descriptors: muscular atrophy, spinal motor neuron disease, genetic therapy, SMA.

Results: SMA treatment was not possible until the end of 2016, and management consisted of supportive measures with a multidisciplinary team. Nowadays, the most effective treatment is related to a drug that prevents or stops complications such as delay or any developing motor milestones, respiratory and swallowing issues. One of the therapies using Zolgensma® is currently the most expensive drug in the world, which amounts to approximately 1.9 million euros per patient, which is administered in a single dose. The drug's mechanism action involves introducing the SMN1 transgene at the motor neuron nucleus to promote SMN protein expression. Another drug is Spinraza®, which was the first oligonucleotide therapy developed for this condition, but it is also costly and needs a dose injection every 4 months to be effective. The drug's mechanism is to incorporate exon 7 into mRNA of the gene SMN2, which promotes an increased production of SMN protein. However, when suspending Spinraza® the beneficial effect is eliminated. Both are therapies that correct the function of systemic nerves, reducing motor neuron loss and also improving strength and muscle tone.

Conclusion: SMA is a severe condition that demands a multidisciplinary approach related to genetic therapy for effective management. It is important to note that despite the oligonucleotide being quite effective in halting the disease, it needs to be administered every 4 months. While the genetic therapy only needs administration one time for life. Although the justification for the high cost includes the fact that both drugs, mainly Zolgensma®, leads to longer survival and motor neuron achievement, based on clinical trials demonstrating safety for patients and encouraging efficacy in SMA type I and II. No long-term effects are described in studies yet and not all of those are accessible to all patients, which is a significant barrier to SMA patients. It is crucial to validate the cost-benefit of these drugs and decrease the price to ensure the majority of patients have equitable access to the treatment.

Keywords: Muscular atrophy. Spinal. Motor neuron disease. Genetic therapy. SMA.

1. Centro Universitário Euro-Americano (UNIEURO)

Knowledge about self-care of children and adolescents with cystic fibrosis in a pediatric specialty hospital

Gabriella Mendes Gonçalves[1]
Rita de Cássia Melão de Morais

Abstract

Introduction: Cystic Fibrosis (CF) is a chronic disease of autosomal recessive genetic origin, which alters the cystic fibrosis transmembrane conductance regulator (CFTR), resulting in systemic clinical manifestations, especially affecting the respiratory and digestive systems. In view of the uncertainty in the disease evolution, it is important that the entire team of health professionals who accompany the patient's case provide clinical care, as well as provide health education and psychosocial support for the child and the family with a view to encouraging the family unit to develop adequate coping strategies, and promoting health in an integral way, as well as equipping children and adolescents to promote their self-care.

Objectives: To identify the knowledge of children and adolescents with Cystic Fibrosis in relation to self-care. To analyze and discuss the knowledge identified in relation to the self-care of children and adolescents.

Methods: This is an exploratory qualitative research, involving 12 school-aged children and adolescents, between 7 and 17 years old, affected by cystic fibrosis and undergoing outpatient follow-up at a pediatric specialty at the Pediatric Public Hospital. Data collection was carried out through a questionnaire about the profile and characteristics of the participants and the second stage of data collection was through creativity and sensitivity dynamics (DCS), called Corpo Saber. Data analysis was thematic.

Results: In the study, female participation was of 8 participants, and 4 male participants. The number of school-aged participants was equal to 5 and that of adolescents was equal to 7. The origin of the patients in the study varied between other states (50%), administrative regions (33.3%) and the capital (16.6%). The knowledge of children and adolescents was classified into thematic units according to their reports. Thematic units are benefits of physiotherapy, physical activity, food and water intake, and medication.

Conclusions: It was concluded that children and adolescents perceive the need for knowledge about the disease and have independence in their own care, praising the importance of planning the assistance of nurses and the multidisciplinary team in the health education process, as in the elaboration of health policies and the development of good communication.

Keywords: Cystic fibrosis. Pediatric nursing. Self-care. Knowledge. Child. Adolescents.

1. Universidade de Brasília (UnB)

Marina Pimentel Freitas[1]
Mirella Jackeline de Andrade Rezende
Luciana de Freitas Velloso Monte[2]
Amanda Cristina da Cunha Arruda
Letícia Mello Matos
Raquel Rodrigues Fonseca da Cunha
Ana Carolina Borges Penalva Ferreira

Abstract

Introduction: Hospitalization involves a profound adaptation of the child to the various changes in their daily routine. Keeping children under the supervision and care of parents or family members in the hospital is a strategy to mitigate the negative impacts of hospitalization.

Objective: Review the literature on the participation of parents in the care of hospitalized children.

Methods: This is an integrative literature review, based on the Child and Adolescent Statute and 5 articles selected from the Google Scholar and PubMed databases, published between 2013 and 2023, in English or Portuguese, using the descriptors: childcare, family, parents, hospitalization.

Results: Before the 1940's, children received nursing care without family members during hospitalization, in order to reduce the transmission of infections, but the emotional impacts of the disease and hospitalization on the child and parents were little considered. From the 1950's onwards, the movement of including parents in the care of hospitalized children began, considering the importance of educating, living together, giving emotional support, and experiencing a reality a little closer than it would be outside the hospital environment. Studies have shown that maternal deprivation was a substantial disturbing factor in mental health, propelling changes in care practices. Other reports indicated concern for the welfare of the hospitalized child and led parents and professionals to discuss the hospitalization process, looking for alternatives to humanize this experience. In Brazil, the regulation was issued in 1990, with the Statute of the Child and Adolescent (ECA), stating that health facilities must provide conditions for the full-time permanence of a parent or guardian, during hospitalization. The adoption of a mother-child joint hospitalization system has enabled the reduction of emotional stress, both of the child and of the family. Moreover, it contributed to the reduction of the incidence of infection and the time of hospitalization, favoring the turnover and availability of beds. In addition, the presence and participation of parents in care allows an approximation to health professionals, strengthening the communication and understanding of both parties, reducing the anxiety of parents, stimulating the bond of parents with the child, favoring the process of coping with the disease, treatment adherence, and the quality of care provided. This contributes to the humanization and safety of healthcare, since there is the establishment of bonds, partnerships, and appreciation of the listening capacity of health professionals, besides generating greater confidence in parents to perform care in relation to the child. Hospitalization can also play an educational role when the health team can provide guidance and training to parents, such as procedures needed in complex health conditions, food care and others.

Conclusion: The participation of parents in the care of hospitalized children was of great importance, as it was able to generate several benefits for small patients, parents, and the health team. Therefore, it is essential to expand this participation in an organized way, as well as to stimulate more studies on the impact of the adoption of this practice.

Keywords: Hospitalization. Hospitalized child. Hospitalized adolescent. Family patient support. Comprehensive healthcare.

1. Universidade Católica de Brasília (UCB)
2. Hospital da Criança de Brasília José Alencar (HCB)

The use of semaglutide in infancy and adolescence: how does it work?

Mario Augusto Rego de Macedo[1]
Adria Maria Nascimento Junior
Arthur Dutra
Kamila Lacerda Dechichi

Abstract

Introduction: Obesity has emerged as a global health epidemic, with its prevalence rising among children. This condition is associated with a plethora of comorbidities, including cardiovascular diseases, diabetes, and certain types of cancer. Despite several efforts to mitigate obesity prevalence, its management remains challenging, especially in severe cases. Semaglutide, a glucagon-like peptide-1 (GLP-1) receptor agonist, has recently emerged as a potential therapeutic option for obesity management in adults. However, its use in children and adolescents with severe obesity is not yet well-established.

Objective and Methods: This paper presents a comprehensive literature review that aims to analyze the effectiveness and safety of semaglutide in children and adolescents. We conducted a thorough search of relevant articles in Portuguese and English from databases PubMed, Google Academics, and The Lancet. In total, eight articles were selected based on specific inclusion criteria, including publication dates between 2018 and 2023. By adhering to these rigorous inclusion criteria, we were able to conduct a robust analysis of the available literature on the use of semaglutide in the pediatric population.

Results: Semaglutide, a GLP-1 receptor agonist, is known to enhance insulin production and reduce glucagon production, thereby lowering blood glucose levels, reducing appetite, improving pancreatic function, and decreasing cardiovascular risk and blood pressure. It primarily acts in the ileum, which is innervated by the vagus nerve, which transmits signals to the brain. In the hypothalamus, it increases the levels of proopiomelanocortin while decreasing the levels of neuropeptide Y and Agouti Related Peptide, leading to increased satiety. However, the use in the pediatric population, particularly in children and adolescents, is not widely recommended, except in cases of severe obesity. Studies have shown that the primary side effects of the treatment were gastrointestinal, such as nausea, vomiting, constipation, diarrhea, dyspepsia, gastritis, pancreatitis, and loss of appetite. Despite a study demonstrating an efficacy rate of 73% in reducing body weight in children and adolescents, the use of this drug can adversely affect the growth and development of children, particularly due to hypoglycemia.

Conclusions: Semaglutide has been demonstrated to be highly effective in reducing severe obesity in adults, although there is currently limited information on its use in the juvenile population. It is important to note that semaglutide acts on the AgRP peptide, which can have a direct impact on the hypothalamic-pituitary axis. This axis plays a critical role in the secretion of the GnRH hormone, which is essential for child development. Therefore, it is essential to use the drug at the recommended dose and only for the specific population for which it was developed to ensure maximum safety. While semaglutide is undoubtedly effective in reducing obesity, its use in the juvenile population requires careful consideration and monitoring to minimize any potential adverse effects on child development.

Keywords: Pediatric obesity. Glucagon-like peptide 1. Obesity management.

1. Centro Universitário Euro-Americano (UNIEURO)

Unidos pela Cura Guide: an instrument to strengthen public policies for early diagnosis of cancer in children and adolescents

Carolina Steinhauser Motta[1]
Thaís Jeronimo Vidal[1]

Abstract

Introduction: In Brazil, childhood cancer is the leading cause of death by disease amongst children and adolescents. In high-income countries, the chances of cure exceed 80%, different from the reality of developing countries. In this context, *Unidos pela Cura* (UPC), a policy to promote early diagnosis, was developed in the state of Rio de Janeiro. Due to this successful policy and the lack of instruments that help health managers prioritize childhood cancer, the Desiderata Institute published, in 2021, the Unidos *pela Cura* Guide: social technology for the early diagnosis of childhood cancer with the objective of promoting the same chances of cure for all children.

Objective: The publication of the Guide aimed to systematize the experience of *Unidos pela Cura* in Rio de Janeiro, in order to help health managers from other territories prioritize childhood cancer through the implementation of early diagnosis policies.

Method: For the elaboration of the Guide, initially, an exploratory descriptive study of the main results achieved with the Policy between 2008 and 2020 in Rio de Janeiro was conducted. Then, the necessary paths for the implementation of an Early Diagnosis of Childhood and Adolescent Cancer Policy in other geographic contexts were systematized.

Results: The UPC enabled 91% of suspected cancer cases in Primary Care to reach diagnostic centers within three business days. A total of 2146 cases were referred, of which 8% were confirmed as cancer. In addition, 4090 professionals were trained to identify its signs and symptoms. The systematization of this experience identified eight important steps for the implementation of a policy for the early diagnosis of cancer in children and adolescents: (1) identification and awareness of key actors, (2) creation of a strategic committee, (3) knowledge enhancement about the local scenario (epidemiological profile, existing services, flow of diagnosis and care) and definition of priorities, (4) formalization of the policy through a term of commitment, (5) organization of a referral flow, defining the investigation and treatment centers, (6) definition of continuing education strategies for cancer suspicion, (7) monitoring of the referred cases and evaluation of the strategy, and (8) consolidation of the early diagnosis policy through inclusion in the State and/or Municipal Health Plans in order to guarantee the continuity of the initiative even with changes in public management.

Conclusion: Despite the recognized importance that early diagnosis assumes in the context of pediatric oncology, there are still few instruments that guide health managers to organize an agile referral flow of suspected cases in Primary Health Care (PHC) to diagnostic centers. The construction of the UPC Guide aims to fill this gap. It can also be used as a reference for national public policies. The experience in Rio de Janeiro proved to be successful in terms of the organization of the flow and the qualification of professionals to identify childhood cancer signs and symptoms. Today, it is a consolidated and recognized policy in Rio de Janeiro, and its expansion to other states can promote the same chances of cure for all children and adolescents.

Keywords: Medical oncology. Early diagnosis. Early detection of cancer. Health policy. Pediatrics.

1. Instituto Desiderata

Bringing hospital and school together: how can they work together?

Sofia Costa e Silva Duarte[1]

Abstract

Introduction: This work (an experience report) was held with the aim of leveraging the teaching and learning processes of CKD (Chronic Kidney Disease) patients, making schools aware of the real needs of these patients, focusing on health guidance on the disease, treatment, care, development aspects and learning difficulties presented by them. There is a need for better guidance to the education network regarding special needs and different forms of support for children with CKD, given that many of these patients do not have access to school rights and curricular adaptations necessary for better academic performance, as well as higher school failure and dropout rates.

Objective and Methods: Among the specific objectives of this event are: to increase the knowledge of teachers about the diagnosis, treatment, special needs and rights of patients with CKD; improve teachers' understanding of the importance of keeping patients up to date with the school context; guarantee patient's rights to access school and pertinent curricular adaptations; sensitize teachers and those involved with what can be done by the patient in a school environment in terms of routine adaptation and treatment support; setting up a partnership process to transpose a humanized view of the schools in relation to the patient's treatment processes; inform the rights, care and treatment processes of these patients in case of hospitalization, treatment and transplantation; promote a space for exchanging information and suggestions for improvement in order to benefit the academic and social life of patients with CKD, with a view to life planning and health promotion. To this end, the event consisted of two online meetings that took place in different shifts (morning and afternoon) to facilitate the participation of teachers, considering their available time. Each meeting lasted four hours. As evidenced by the online participation, an important quorum was obtained, with answers to questions through the participation of the teachers.

Conclusion: It was considered that the event was a pioneering initiative of cooperation between elements of the childcare network, and that it will serve as an example for other initiatives.

Keywords: Humanization of hospital care. Teaching (DO13663). Pediatrics. Development Psychology. Child Psychology. Hospitalization.

1. Hospital da Criança de Brasília José Alencar (HCB)

Use of the clinical deterioration scale in oncohematology patients: analysis of a Brazilian tertiary pediatric service.

Ana Paula Querino Belluco[1]
Isis Maria Quezado Magalhães[2]
Cristiane Feitosa Salviano[2]

Abstract

Introduction: Early detection of recognizable signs of clinical deterioration in hospitalized patients is critical for decision-making by a multidisciplinary team to avoid serious, preventable complications. Oncohematological patients require special care in this scenario, due to the aggressiveness of their clinical conditions and treatments. Multiple systems for early detection of clinical deterioration have already been developed with the aim of reducing the rate of serious outcomes in hospitalized patients, among which the Pediatric Early Warning Systems (PEWS) stand out for the pediatric population. Despite the good results demonstrated internationally, multiple challenges involve its wide insertion in the current hospital systems.

Objectives: The present study aims to analyze the main difficulties and barriers in the implementation of a PEWS model in a tertiary pediatric hospital in Brasília, Federal District.

Methods: We retrospectively evaluated the medical records of 39 patients aged between 0 and 17 years, hospitalized for oncological and/or hematological conditions, who underwent unplanned transfers to intensive care units. The evaluation consists of a serial analysis of 4 parameters (behavioral, cardiovascular, respiratory and blood pressure) to be performed at least 6 times a day, in which the final score is associated with an algorithm of proposed interventions. The goal is to increase surveillance in patients with higher scores and reduce the rate of critical interventions. The quantification of errors was performed through a subsequent reanalysis between the PEWS scores and the data obtained from the medical records.

Results: Only 35 of the 39 cases were selected for study. The results showed a high incidence of errors in the evaluations, with more than 70% of the analyzes performed incorrectly. In parallel, a high number of critical interventions and severe outcomes were detected, which occurred in 17 of the 35 patients, including 6 deaths. The incorrect analyses were, in 63%, underestimated, with the cardiovascular item being the most frequently incorrectly evaluated criterion.

Discussion: There are few studies that characterize the insertion of the PEWS score in hospital services, especially regarding the approach to the difficulties faced in implementing it. Recording errors, the absence of adequate marking options during the analysis and the number of criteria evaluated per parameter are factors that may have influenced the high prevalence of errors in the evaluations of this research, data that are in line with the literature. Other factors that may be related are the large number of patients assisted by a professional, the insufficient training time provided to them and the lack of standardization of the analyses, elements that are deeply linked to the quality of the evaluations. Such attributes may be related to the high rate of critical interventions and severe outcomes in these patients.

Conclusion: Based on the data presented, it is concluded that the process of implementing early detection systems requires parallel studies to improve functionality at the level of care. There is a need to improve the scale as well as its application for better usability and safety in its use.

Keywords: Clinical deterioration. Pediatric hospitals. Hematology. Oncology. Hospitalization.

1. Universidade de Brasília (UnB)

2. Hospital da Criança de Brasília José Alencar (HCB)

Voice through paper: children's drawings and the perception of children with cancer on families and treatment

Acimar Gonçalves da Cunha Júnior[1]
Sofia Costa e Silva Duarte[1]

Abstract

Introduction: The act of drawing is a unique record of subjectivity. It is the representation of time clipping, impression of the characteristics of the child's development. Drawing can express what speech still cannot, for children, adults and seniors of all ages. The graphic representation is full of meanings of the child's subjective reality, their family, cultural, routine and learning aspects.

Objective and Methods: This article aims to analyze, the perceptions of children with cancer about their family and treatment, based on drawings. The methodology used for the development of this study was of a basic nature, with a qualitative and exploratory research approach. For this purpose, the Drawings of Families with Stories (DF-E) instrument was chosen. Such an instrument allows an approach to conflicting points and emotional commitments in the family system through graphic expression and free association. Five hospitalized children were observed, and their respective families were interviewed. The children were invited to create four graphic productions, with the themes: 1) draw any family, 2) draw a family you would like to have, 3) draw a family where someone is not well, and 4) draw your family. After each production, the child was asked to tell a story for each drawing and give that work a title. The drawings were made individually, without intervention of any other family members. The objective of the analysis was to evaluate their coping with the disease, family support, and possible transactional reconfigurations in this system.

Results and Conclusion: The analyses of all productions generated the following analysis categories: stage of development, self-perception, family perception, illness perception, needs and desires, anxieties, and difficulties. Hair loss impact, child's socialization interference, desire for material goods, aspects of coping with the disease with fantasy elements (superheroes) were identified. Some children showed a pattern of low interaction during the activity. Finally, the findings showed that children's drawings significantly expressed the children's stage of development, their family relationships, as well as their dreams, sufferings, projects, fears and perspectives for the future.

Keywords: Children's drawings. Children. Cancer. Family.

1. Hospital da Criança de Brasília José Alencar (HCB)

WORKS PRESENTED IN THE ELECTRONIC POSTER MODALITY

Advances with the use of cannabidiol in the treatment of refractory epilepsy in children: a literature review

Lorena Miranda Lorens[1]

Abstract

Introduction: Epilepsy is one of the most common neurological conditions in children. Most children with epilepsy respond to antiepileptic drugs (AEDs), but approximately 30% of children develop drug-resistant epilepsy (DRE). DRE is associated with serious consequences, including seizures, increased mortality, and cognitive deficits. As a result, interest in the use of cannabis-based treatments for pediatric epilepsy has been growing in the last decade. Although its mechanism of action is still unknown, nine-delta-tetrahydrocannabinol (THC) and cannabidiol (CBD) have received the most attention as potential antiepileptic agents, mainly in Dravet and Lennox-Gastaut syndromes, appearing to be the best-known option.

Aim: This work aims to explain how Cannabis-based products can be a great option as palliative therapy to reduce the symptoms of children patients with Epilepsy, showing possible harms and benefits.

Method: Exploratory qualitative review of literature, carried out from the electronic search in the PubMed database, using the descriptors Cannabidiol, Epilepsy and Childhood for a careful study of the subject. 6 articles in English and 1 in Portuguese from the last 7 years were selected. Only original articles were selected, and monographs, theses, dissertations, and opinion letters were excluded.

Results: Although the precise mechanism of action remains unknown, recent evidence has shown that cannabidiol reduces neuronal excitability through the following effects: desensitization of TRPV1 receptors, inhibition of adenosine transport and activation of the PI3K pathway. The PI3K pathway seems to be involved in reducing glial cell activation – cells located in the brain that provide physical and metabolic support to neurons, which are activated in response to seizures, contributing to inflammation and brain damage – helping to control the seizures and neurodegeneration. One of the analyzed clinical trials has shown that, among children with Dravet syndrome who received CBD, 5% (3/61) experienced freedom from all seizures, while no child in the placebo group became seizure free over a 14-week treatment period. However, studies have shown that the CBD therapy caused gastrointestinal adverse events, such as vomiting and diarrhea and changes in sleep patterns, as seen in a few children, where sleep apnea was reported. Also, some trials reported deaths in the group of children who received the CBD, but those were due to other causes, not related to the treatment. In general, despite the harms, patients using CBD have shown significant improvements in quality of life and available evidence suggests that cannabidiol reduces seizure frequency among children with drug-resistant epilepsy (moderate certainty). Moreover, the evidence base is primarily limited to CBD and no data is available for other cannabis-based products.

Conclusion: On the basis of the results presented, available studies support CBD as an effective treatment option for reducing the frequency of seizures among children with drug-resistant epilepsy, helping to improve quality of life. In addition, some children have experienced complete seizure freedom and that is why the importance of encouraging new research in this area becomes evident. This is an active area of research and future updates will include additional evidence as it becomes available.

Keywords: Cannabidiol. Epilepsy. Childhood.

1. Universidade Católica de Brasília (UCB)

Analysis of gastrointestinal symptoms presented by patients admitted to a pediatric oncological palliative care service in the Federal District

Stefâni Soares dos Anjos[1]
Gabriella Silvestre Paiva[1]
Beatriz Christina Luzete[2]

Abstract

Introduction: Palliative Care aims to promote quality of life for patients and their families. Nutritional assessment helps to identify changes, generating prevention and relief of suffering. Gastrointestinal symptoms can impact the patient's weight, nutritional status, quality of life, relationship with food and other physical, psychological, and social aspects. Therefore, gastrointestinal symptoms and the impact they generate on patients' quality of life must be observed and properly analyzed so favorable adjustments can be made.

Objective: To evaluate the gastrointestinal symptoms presented by patients admitted to a Pediatric Oncology Palliative Care Service in the Federal District.

Methodology: Descriptive study, with retrospective, prospective and quantitative collection and analysis, using the MV 2000 electronic medical record, documents and internal reports prepared by the Palliative Care (PC) team. Pediatric patients admitted to the PC service from 2017 to 2022 were included, excluding those who did not agree to participate and those who did not present the available data. The study was approved by the CEP (CAAE: 45710721.5.0000.0144).

Results and Discussion: The study was applied to 98 cancer patients aged between two months and 21 years. 53% of patients had some type of gastrointestinal symptom (n=52). Among the symptoms reported on admission, the following were detected: 31.36% (n=32) of nausea and vomiting, 10.8% (n=9) of constipation, 7.84% (n=8) of dysphagia, 6.86% (n=7) of abdominal distention, and 5.88% (n=6) of diarrhea. These symptoms can lead to reduced oral intake and weight loss, and in this study, 37% of patients with nausea and vomiting had weight loss (n=12). Malnourished patients had significantly more weight loss and less weight gain. Patients with dysphagia were using an adapted oral diet or enteral diet. For the control of symptoms it is possible to use pharmacological and non-pharmacological measures. Among patients who had any gastrointestinal symptoms, 88% received nutritional guidance for symptom relief (n=47). The various factors evaluated during the study have an influence on the nutritional status of pediatric cancer patients admitted to palliative care, and when evaluating them, one must understand the possible contributions to reverse underweight or overweight. The present relationship between gastrointestinal symptoms and low weight is a factor that raises the need to understand the influence of these symptoms on the nutritional and general well-being of the patient, in order to promote effective interventions capable of promoting improvements in the care of pediatric cancer patients admitted to palliative care.

Conclusion: Pediatric patients in palliative care have a high prevalence of gastrointestinal symptoms that need to receive adequate attention from the multidisciplinary team for their appropriate control and relief. Early detection of symptoms that may affect patients' nutritional status promotes immediate adequate care responses, and the prevention of unwanted and/or reversible symptoms**.**

Keywords: Oncology. Palliative care. Child health. Nutritional profile. Gastrointestinal symptoms.

1. Universidade de Brasília (UnB)
2. Hospital da Criança de Brasília (HCB)

Applicability of artificial intelligence in pediatric airway management and training of medical professionals: a narrative review

Raíssa Rebeca Albuquerque Cavalcante
Anna Carolina de Oliveira Chaves
Caio Henrique Macedo Nascimento
Jéssica do Nascimento Oliveira Rodrigues
Maria Paula Alves Rabêlo
Getúlio Bernardo Morato Filho
Ana Lúcia Quirino de Oliveira

Abstract

Introduction: Currently, artificial intelligence (AI) has been used in different areas of medicine to enhance patient care through assertive diagnoses and minimally harmful procedures. In this sense, there is the possibility of using this tool for airway management in pediatric patients, avoiding adverse effects and ensuring a better prognosis.

Objective: To understand the possibilities of using AI in airway management in the pediatric population, how it can help in the training of professionals, and the efficiency of the procedures involved in this management.

Method: A narrative literature review was conducted using the search strategy (artificial intelligence OR machine learning OR deep learning) AND (airway OR intubation) AND (children OR pediatric) in the PubMed database, filtering for articles published in the last 5 years. This resulted in 109 articles, whose titles and abstracts were read. Those that did not fit the desired theme were excluded. After this step, 25 articles remained, which were read completely. Another 14 texts were eliminated at this stage, leaving 11 articles which were used in the review.

Results: With this review, it was found that there are some proposals for the use of AI in airway management in the pediatric population. It is especially important to consider the specificities of this population, as these patients have anatomical differences compared to adults, which cause difficulty in performing the intubation procedure, and often are uncooperative with health professionals. In this sense, AI can be useful in several ways. Before the intubation procedure, it can evaluate the degree of difficulty of the process, possibly being more effective than the commonly used LEMON (look, evaluate, Mallampati, obstruction, neck mobility) protocol. During intubation, AI can also assist in choosing the most appropriate tracheal tube by using mathematical approximations to integrate complex associations of clinical data, and by identifying in detail the upper airway anatomy and assisting to classify it in real time. Furthermore, training in endotracheal intubation, bronchoscopy, and laryngoscopy is currently done on mannequins, and evaluated by human supervisors, who may provide inconsistent assessments. With AI, parameters can be used to evaluate such procedures impartially and indicate errors during execution. An example is the use of a dilated convolutional neural network capable of identifying essential factors such as time and movement during intubation, providing accurate assessments with scores, and offering valuable feedback to instructors on the performance of pediatric trainees.

Conclusion: Therefore, AI may be an important tool for airway management in pediatric patients, both by assisting in the practice of endotracheal intubation and other procedures, and by improving the proficiency of trainee professionals. This can lead to a reduction in morbidity and mortality related to errors in this practice. Thus, it is important to conduct further studies, especially in the pediatric population, in order to improve and validate existing technologies.

Keywords: Artificial Intelligence. Airway Management. Pediatric Intubation.

Artificial intelligence in radiological diagnosis and its pediatric use

Pedro Augusto Gonçalves dos Santos[1]
Ana Beatriz Caetano Santos de Sá
Ana Clara Monte Varandas
Beatriz Eler de Lima
Ana Clara Moreira Almeida
Helena Monte Varandas
Caio Toscano Lessa

Abstract

Introduction: Artificial intelligence (AI) is a software that automates some cognitive tasks and being a mechanism of wide application, it has been gaining space in various medias. In medicine, it has been used in radiology, pediatrics, and clinical surgery, helping doctors in the process of detecting and diagnosing the most varied diseases. There are still several barriers to its full implementation, such as workers' fear of losing their jobs to new technologies. But AI has shown to be very beneficial and promising.

Objectives: This review seeks to discuss and analyze the characteristics, specificities and advances brought by artificial intelligence to medicine, especially in pediatrics.

Metodology: An active search was carried out in PubMed, Scielo and Lilacs databases, using the descriptors 'children', 'artificial intelligence' and 'radiology', and using the constraints 'free full text', 'full text' and 'review', choosing studies from the last five years. After the search, 61 articles were found, and, by organizing and selecting them, thematically, 6 were analyzed and included in this review.

Results: The main objective of implementing this technology in medicine is to assist and optimize the work of the doctor, improving patients' experiences and increasing their chances of recovery. Currently, artificial intelligence is already used to discover an individual's bone age, but has several other uses and benefits that have been debated: optimization of the radiation dose in pediatric radiological examinations, where children are more susceptible to the harmful effects of ionizing radiation, early detection of diseases by analyzing patterns and comparing examinations, finding bone problems that would affect the child's development, decrease in reading time, anticipating doctors' decision-making, and enabling action in even earlier stages of the disease. One of the main reasons that has been barring these technologies from the market is the wide range of sizes, body compositions and anatomy, mainly, in children who are still developing, which delay the machine learning process. Therefore, the medical uses of artificial intelligence are still being evaluated and studied but reach several areas of action and influence. That's why it is important to stimulate the debate, whenever possible.

Conclusion: Artificial intelligence, despite having great potential, is still under-tested and its effectiveness is still up for debate. However, the benefits and changes it may offer are already appearing in current medicine, revolutionizing the way images are analyzed and diagnosed. Thus, it is evident that in the future it will have a bigger role in medicine, changing the way radiologists and doctors in general work.

Keywords: Child. Artificial intelligence. Radiology.

1. Universidade Católica de Brasília (UCB)

Assessment of Brazilian shortage of medical supplies in a public tertiary pediatric care in the Midwest in 2022

Kalina Kelly Alves Ribeiro[1]
Leandro Pereira Bias Machado[1]
José de Alsimir Gomes Junior[1]
Maria Eduarda Silva Miranda[1]
Renato da Silva[1]

Abstract

Introduction: In 2022, several government councils and technical-scientific societies raised concerns about the shortage of medical supplies in Brazil. These shortages were motivated by the repercussion of residual effects caused by the increase in hospital needs demanded by the COVID-19 public health emergency, alongside the Russo-Ukrainian War, since those are major commodity chemical producers. As a result, supply chain management has become a major challenge in meeting complex health needs in Brazil.

Goal: Describe the shortage of medical supplies during the shortage era in Brazil in 2022, in a Public

Tertiary Pediatric care in the Midwest.

Methods: A survey was carried out assessing the technical reports addressing on the risks related to the shortage of medical supplies, released by the pharmacy department, between January to December 2022. The identified drugs were classified by criticality (ABC-VEN Matrix) and a therapeutic categories model guideline (WHOCC/ATC). In order to assess the mitigation strategy, it evaluated the contractual clauses and records of warnings to the suppliers related to the delayed delivery. The acquisition processes carried out during 2022 were also verified, to detect changes in cost and failure rate in those acquisitions.

Results: During the period, 55 technical reports of shortage risk were released, 46 for drugs and 9 for medical materials. When compared to the total of items in the prescription drug/material list, the percentages of items at risk of shortages were 12% for drugs and 1% for medical materials. As for the VEN-matrix classification, 18% (10) were classified as non-essential, 47% (26) as essential and 35% (19) as very essential items. When evaluating the therapeutic classification (WHOCC-ATC), the drug classes most frequently used were nervous system 22% (10), anti-infectives for systemic use 17% (8) and respiratory systems 13% (6). Regarding mitigation strategies, 40% of the acquisition processes that were initiated in an attempt to mitigate the shortage of medical supplies failed, whilst 31% were successful. The remaining 29%, consisted of 20% of non-essential items, with the possibility of matching the delivery expectation given by the supplier in 5% and it was possible to call others supplies that were qualified in the regular acquisition process, and in the remaining 4% of cases it was necessary to carry out an emergency acquisition processes, verifying the necessity and a possible shortage risk of the product. With regards to the costs of processes that succeeded, there were an average increase in value of 43% (SD ± 109%), with the greatest raise due to the acquisition of injectable atropine, which had an increase of 497% in the price per unit, from R$2.89 to R$17.24.

Conclusion: The difficulty during the year 2022 in the scenario of the Brazilian supply of health products was evidenced, with a risk rate of shortages of 12% for medicines and 1% for materials in relation to the list of prescription products. This scenario corroborated an increase in market values above the sector's rates, and, in some cases, resulting in lack of products availability, generating shortages, and demanding the use of mitigation alternatives.

Keywords: Shortage. Medicines. Hospital medical supplies.

1. Hospital da Criança de Brasília José Alencar (HCB)

Assistive technologies: quality of life of children with cochlear implant – literature review

Micaela de Jesus Lisboa[1]
Yasmin Farias Ribeiro
Manoela Marçal Romeiro Barbosa Cordeiro
Júlia Viana Mendes
Viviane Costa e Silva
Larissa Tavares Gomes
Mikaelly da Silva Sousa

Abstract

Introduction: Hearing is one of the five human senses that directly influences communication and social interaction, which are fundamental for the psychosocial development of children, especially in the first years of life. According to Loy et al (2010), children with hearing loss have greater difficulty adapting to different environments and making friends, in addition to having feelings of not having a long life, characteristics that interfere with the quality of life of these people from childhood to adulthood, both in the family and in the educational context. In cases of sensorineural hearing loss, the cochlear implant can be used as an intervention measure. It is an electronic device surgically inserted into the cochlea, and its process has been carried out usefully and with the need for evaluation by an interdisciplinary team (AMARAL *et al.*, 2019).

Objective: To analyze the importance and effectiveness of assistive technologies and the impact on the quality of life of children using cochlear implants.

Methodology: Integrative review of publications, using as inclusion criteria: articles published in the last 15 years in Portuguese and English, with the descriptors (DECS): Sensorineural Hearing Loss, Cochlear Implant, Child Health, Hearing Aids and their correlates in English language (MESH): Sensorineural Hearing Loss, Cochlear Implant, Child Health, Hearing Aids, available in full in the following databases: Cochrane Library, Lilacs, Scielo and PubMed/Medline. Each author searched a particular database and analyzed the articles to describe the results.

Results: A total of 1058 articles were identified, and from these 22 were selected: PubMed/Medline (13), Lilacs (3) Scielo (4) Cochrane (2). Through the literature review it was found that in relation to the spoken language, children who had the cochlear implant before the age of 12 months showed greater success for development, especially when correlated with an effective rehabilitation (TANAMATI, 2011).

Conclusion: For the child to be successful with cochlear implantation, according to Fortunato Tavares et al (2012), it is necessary, first of all, for the family to be able to perform all phases of the process. All efforts should be directed towards the complete and differential audiological diagnosis that will allow the baby to achieve language development. The rehabilitation process is long, and therefore, early auditory stimulation is essential for the best use of auditory residues and to allow the child to achieve the broader goal of habilitation, which is communicative competence (SCARABELLO *et al.*, 2020).

Keywords: Sensorineural Hearing Loss. Cochlear Implantation. Child Health. Hearing Aids.

1. Universidade de Brasília (UnB)

Autoimmune lymphoproliferative syndrome due to FAS mutation: a case report on genetic testing and functional assay

Bruna Cândido Guido[1]
Anna Carolina Silva Dias[1]
Robéria Mendonça de Pontes[1]
Agenor de Castro Moreira dos Santos Junior[1]
Karina Mescouto Melo[1]
Ricardo Camargo[1]

Abstract

Introduction: Autoimmune lymphoproliferative syndrome (ALPS) is a rare genetic disorder caused by mutations in genes involved in apoptosis, which leads to the accumulation of autoreactive lymphocytes, chronic lymphoproliferation, autoimmune cytopenia, and an increased risk of lymphoma. FAS gene mutations are the most common cause of ALPS, accounting for 50-60% of cases. ALPS usually presents different penetrance for cellular and clinical phenotype and between males and females, being predominant in males. Here, we present a case report of a 10-year-old boy diagnosed with ALPS-FAS, who initially presented multilineage cytopenia.

Goals: The goal of this study was to investigate the clinical and cellular phenotypes associated with FAS mutations in a family with a history of ALPS.

Methods: Immunophenotypic analysis by flow cytometry and Sanger sequencing were performed to identify mutations in FAS and CASP10 for the patient index and nine family members. Next-generation sequencing (NGS) analysis, using an autoinflammatory syndrome panel of genes, and functional apoptosis study to assess defects in apoptosis were conducted for the index and his parents.

Results: The index patient initially presented cutaneous rash, fever, and multilineage cytopenia, which were treated with blood transfusion and antibiotics. During the follow-up, chronic lymphoproliferation, high levels of serum vitamin B12, IL10 and IgG, and increased percentages of circulating double-negative T cells (CD3+TCR+CD4-CD8–) were identified, leading to the suspicion of ALPS. Genetic analysis confirmed FAS mutation inherited from his asymptomatic father. NGS sequencing showed that the index patient had the following mutations: FAS c.748C>T: p.(Arg250Ter), CASP10 c.1202_1208del: p. (Cys401Leufs*15), and LRBA c.2450-7C>T: p. where the first one was pathogenic and the others of uncertain significance. His father, although asymptomatic, had the same two ALPS-related mutations (in FAS and CASP10), and his mother presented the mutation in LRBA. All the paternal relatives had FAS mutation and two, besides the father, also had CASP10 mutation. Flow cytometry analysis showed low FAS surface expression on CD8 cells of the proband, his father and all the paternal relatives, however, increased percentages of double-negative T cells (DNTs) which were just observed in the proband and in male relatives. The mother and his sister had normal percentages of DNTs. Preliminary data from the functional apoptosis assay showed that both the index patient's and father's effector memory T cells and DNT cells presented defects in FAS-mediated apoptosis.

Conclusion: ALPS is a complex disorder that can present a wide range of clinical manifestations. The family study showed that, according to the literature, despite the index's father having no clinical manifestations, showing reduced penetrance for the clinical phenotype, he presented defective FAS-mediated apoptosis cellular phenotype. The identification of the FAS mutation in the index patient and his family members allowed for early diagnosis and appropriate management, which is crucial in improving outcomes for ALPS patients. This study highlights the importance of genetic testing and functional assays in the diagnosis of ALPS-FAS in a family with a history of ALPS, which can aid in the early diagnosis and management of this rare disorder.

Keywords: Autoimmune lymphoproliferative syndrome. FAS mutation. Cytopenia. Apoptosis. Immunophenotyping. Functional apoptosis assay.

1. Hospital da Criança de Brasília José Alencar (HCB)

Brazilian epidemiological profile of leukemias in children aged 1 to 10 years

Thales Queiroz Souza[1]

Abstract

Introduction: The quantification of data for children with complex health conditions can be a challenge. The identification of households in this context, enables the diagnosis, treatment and monitoring of these. In view of the current unstable and low average rates of home visits, there is evidence that the aid does not reach those in need, especially children. Thus, the importance of evaluating the data already collected is validated, in order to understand which areas demand more assistance, and how health teams can condition quality of life for these patients.

Objective: To describe the regional epidemiological profile of leukemia in the pediatric age group in Brazil over 10 years.

Method: Observational, descriptive, and cross-sectional data collection in DATASUS on diagnosis and treatment time of cases of lymphoid, myeloid, monocytic, and cell-type leukemias of unspecified type, in children under 1 year to 10 years, for a period of ten years – January 2013 to February 2023.

Results: A higher number of diagnoses at all ages is identified in the southeast region, with a total of 3,768 diagnoses, 33% of the total (11,147). The Midwest region accounts for 8% of the diagnoses, the region with the lowest number of diagnoses. There are 1,548 ignored cases, therefore without therapeutic approach (no surgery, radiotherapy, chemotherapy), representing 13.8% of the sample. We noticed that the therapeutic approach of up to 30 days of duration has significant representation (87.4%), followed by treatment lasting more than 60 days (9.04%) and 31 to 60 days (3.4%). Moreover, there is a peak in the treatment of up to 30 days in patients with two (1,293) and three years (1,266).

Conclusion: Data collection is restricted to the initial basis of approach for the care of children diagnosed with leukemia, which points to the need of an integral action of the health system for the diagnosis, staging and treatment, including the sequelae of functional impairment. From the diagnoses by regions we questioned the possibility of migration of children from other regions in search of care in the Southeast region, but this situation represents only 0.048% of the total cases, suggesting exclusion of the migratory hypothesis. The low diagnosis rate in the Midwest region can be correlated with the low mean number of home visits in the region. The treatment profile and the age peaks ratify the literature on the epidemiology of this disease in the country. Thus, different lines for understanding the context of the follow-up cycle, treatment, remission, and relapse of these patients are evidenced. It is urgent to continue the collection of epidemiological data, with attention to the tracking of patients aged one to three years, and to primary care in the southeastern and northeastern regions of Brazil.

Keywords: Leukemia. Myelomonocytic. Juvenile epidemiology.

1. Universidade de Brasília (UnB)

Burns in childhood: epidemiological profile of hospitalizations as a guide for accident prevention in Brazil

Marina Gonçalves de Castro Moreira dos Santos[1]
Matheus Passos de Moura
Laura Vieira Pericole

Abstract

Introduction: Burns in childhood are a significant cause of trauma and accidental deformities in the Brazilian child population. Given the potential severity of burns in this age group and their avoidable nature, the incentive for preventive practices should be reinforced through an epidemiological approach that allows for better understanding of this context.

Objective: To analyze the Brazilian epidemiological profile of hospitalizations for childhood burns among children aged 0 to 9 years from 2018 to 2022, in order to design appropriate preventive strategies.

Method: This study is a descriptive epidemiological analysis, based on data of hospitalizations for burns in Brazil – involving children aged 0 to 9 years. Data were collected from the SUS Hospital Information System (SIH/SUS) in the period 2018 to 2022, available from the Department of Informatics of the Unified Health System (DATASUS).

Results: A total of 6.770.239 hospitalizations of people aged 0 to 9 years, of which 34.835 correspond to burns – equivalent to 0,5% of the total – were found during the stipulated time frame. Among the notifications of hospitalizations for burns, 32.624 (90,7%) were urgencies. Regarding the proportion of hospitalizations for burns in persons aged 0 to 9 years by gender, a considerable prevalence was observed among the male population with 20.992 hospitalizations compared to 13.913– so male population makes up 60,06% of the injured population, considering the age group in question. As for the age group segment, the most prevalent in relation to hospitalizations was from 1 to 4 years old, which accounted for 22.479 of cases (64,53% of total cases). Moreover, in an analysis by region, the northeast region that, in all, accounted for 11.214 hospitalizations, corresponded to approximately 32,19% of the number of hospitalizations for burns, being the region with the highest prevalence of this type of injury in the country.

Conclusion: Faced with an annual average of 6.967 hospitalizations, the importance of prioritizing measures for better healthcare to burn victims in childhood is evident, as well as promoting alternatives for safety in the home environment. Moreover, there is a prevalence of injuries involving male children between 1 and 4 years of age – this should therefore be the target audience for campaigns to encourage protection against burn accidents.

Keywords: Burns. Child health. Epidemiology.

1. Universidade Federal de Jataí

Clinical characteristics of patients with SARS CoV2 infection in a pediatric hospital using the WHO Global Clinical platform

Ivo Medeiros[1]
Cristiane Feitosa[1]
Hevelin Silva[1]
Luciana Monte[1]

Abstract

Introduction and Objective: To describe the clinical and epidemiological profile of cases of SARS-CoV-2 infection from March 2020 to May 2022 followed in a Brazilian pediatric hospital, reported to the WHO Global Platform.

Methods: This is an observational and descriptive study, based on the collection of clinical data from patients with a confirmed diagnosis of SARS-CoV-2 infection and on follow-up in outpatient clinics and inpatient units of a Brazilian hospital since the beginning of the COVID-19 pandemic, until May 2022. The data collected was linked to the Global Clinical Platform COVID-19, a tool developed by the WHO, through the Smart Health Connect (SHC) platform, for the collection and systematization of anonymized data through artificial intelligence (AI).

Results: A total of 465 positive cases for SARS-CoV-2 were identified between 0 and 87 years of age, predominantly male (55.7%, n=259). As it is a pediatric hospital, there was a predominance of the age group 18 years old: 91.8% (mean age 6.5 years old. The highest percentage of cases occurred in children up to 3 years old. The age group > 18 years, equivalent to 8.2% (38 adults), had a mean age of 47.4 years. Most of the cases included in the study were in hospital, due to the easier access to diagnostic tests for the infection in this unit. Severe Acute Respiratory Syndrome was diagnosed in 186 (40%) patients, and Multisystem Inflammatory Syndrome in Children related to Covid-19 (MIS-C) in 44 cases (9.5%). With regard to clinical severity, occurrences were classified from asymptomatic to severe/critical: mild cases predominated (60.0% n = 279). The fatality rate was 6,4 (n=30). Half of the deaths were of patients aged 18 years or older. Of those younger than 18 years old, 4 cases occurred with infants younger than 1 year old and males were predominant (60.0%, n=9). Focusing on pediatric cases, only two had no previous history of comorbidity, having MIS-C as a clinical manifestation. As the study took place in a high complexity hospital, the profile of the patients studied was similar to that of patients treated at the hospital. The main previous comorbidities of the patients were neurological, cardiological, onco-hematological and hepatological disorders. Three deaths were of children with Down syndrome were registered. Regarding the use of AI, there was a need for adjustments in the capture of technical terms and improvement of the capture, in order to obtain more clinical data of the included patients.

Conclusion: This study demonstrates that most cases of SARS-CoV-2 infection in the pediatric age group analyzed had mild symptoms and a good outcome, even those with preexisting complex diseases. The use of AI tools for capturing and analyzing data were extremely useful, considering that this is a study with a large number of patients, and technical adjustments still need to be made to enable more substantial data collection.

Keywords: SARS-CoV-2. COVID-19. Clinical Evolution. Pediatrics

1. Hospital da Criança de Brasília José Alencar (HCB)

Care through play: the contributions of hospital pedagogy in the pediatric treatment of medium and high complexity diseases

Isadora Dias Robayo[1]

Abstract

Introduction: The purpose of Hospital pedagogy is to bring hospitalized patients a ludic and humanized approach, to make the hospitalization process less distressing and apprehensive. In addition to pedagogy being a form of humanization and care, it is also important for the rehabilitation of patients who developed sequelae due to diseases.

Objective: Based on an experience report, the present work aims to describe the contributions of playful activities in the treatment and recovery process of children and adolescents affected by medium and high complexity diseases, hospitalized in a public hospital in Brasília.

Method: The pedagogical practice in the hospital involves planning and executing activities with hospitalized children, either in hospital play area rooms or on the hospital bed itself. The main purpose of care through playing is to involve children in games and activities, reestablishing bonds that are often left aside during the treatment process and hospitalization time. Through these activities, the social reintegration of children is considered an important element through contact with other patients who, due to complex health conditions, are away from school and their daily routine with friends and family. This socialization takes place in play area rooms in which the entire structure is planned to promote ludic care through board games, book reading, play and handicrafts, which are often performed together with patient carers.

Results: Based on the ludic interventions described above, we observe a reduction in the anxiety levels of patients and their caregivers, who find themselves in a vulnerable situation, away from home and in an environment that often creates fear and anguish. As mentioned by the literature, hospital pedagogy intends to re-signify a patient's life. It provides well-being, care, and promotion of self-esteem through the interventions and activities developed. It is worth mentioning that pedagogical planning is entirely thought out based on the physical and mental health conditions of patients.

Discussion: In conclusion, based on real experiences, it is noticeable that hospital pedagogy through playing contributes significantly to the health treatment of hospitalized children and adolescents. It encourages, through games and playing, social interaction between patients. In addition, it stimulates creativity and imagination, providing patients and their companions a peaceful and welcoming environment.

Keywords: Hospital pedagogy. Humanization. Playfulness. Technologies in the panorama of care.

1. Hospital da Criança de Brasília José Alencar (HCB)

Caring for the caregiver: experience report about care for parents of children with complex health conditions

Rebecca Camurça Torquato
Eilen Tainá Matos Ferreira
Angelo Ramos Junior
Luana Nunes Caldini
Cristiana Brasil de Almeida Rebouças

Abstract

Introduction: Children with complex health conditions require an intense care routine. This assistance is offered by teams from different areas of health services, as well as by family members responsible for the performance of this care in the home environment. In this regard, the family needs to adapt and have time to face a new reality. Parents and caregivers experience a routine change in the care of these children, in which they often have to give up their work and daily activities to respond to this new family context.

Objective: To report the experience of nurses in caring for parents of children with complex health conditions in a long-term hospitalization unit.

Method: This is a descriptive experience report study carried out by nurses in the Special Care Unit of a reference pediatric hospital in Ceará, Brazil, from May to December 2019.

Results: The Special Care Unit assists children with complex health conditions who remain hospitalized for long periods. In the unit, caregivers, mostly mothers, are trained to provide care for children and, therefore, there is a need for them to be constantly present in the premises, in a tiring routine. To promote moments of care for the caregivers' mental and physical health, relaxation activities were carried out, such as music therapy and senior dance, manual activities such as crafts and painting, celebration of festive dates, such as *São João*, and the joint assembly of the ward's Christmas tree, conversation circles about breast cancer prevention in reference to *"Outubro Rosa"* in addition to practices involving the stimulation of the caregivers' self-esteem, where makeup and hairstyling services were offered to the mothers. The caregivers were very receptive to the professionals and showed interest in participating in the activities.

Conclusion: It was noticed that the activities carried out in the unit were important to offer caregivers moments of entertainment and self-care amid an exhaustive routine. Such activities favored the relaxation and health promotion of these mothers by reminding them that it is also essential to take care of the caregiver, so that their physical and mental health are preserved during the intense childcare process. In addition, these moments were intended to offer lightness and improvement in the quality of life of such family members during the hospital routine.

Keywords: Caregivers. Children's Chronic. ease. Humanization of Assistance. Nursing.

Challenges and achievements implementing and conducting a pediatric clinical research site: an experience report

Hévelin Silveira e Silva[1]
Paulo Ricardo Ferreira do Nascimento[1]
Analice Sofiste Lima de Freitas[1]

Abstract

Introduction: Clinical research is understood as investigations carried out with the participation of human beings, and which aim to promote more quality of life and longevity for the population. Historically, there are reports that clinical research has been used since ancient Egypt, with the Nuremberg Code (1947) and the Universal Declaration of Human Rights (1948) as landmarks. In Brazil, clinical research was regulated in 1996, creating the National Research Ethics Commission (Conep) and approving regulatory guidelines and standards, thus beginning the consolidation of clinical research at the national level, currently regulated by Resolution Nº 466 of 2012 of the National Health Commission/Ministry of Health (CNS/MS). Considering the benefits of research in the instrumentalization of care, the *Hospital da Criança de Brasília*, according to its declared institutional vision, seeks to be recognized nationally and internationally as a site of excellence in specialized pediatric care and a reference in teaching and research. In order to achieve these goals, clinical research is a possibility of incorporating knowledge about procedures, new diagnostic and therapeutic technologies to the benefit of the pediatric population.

Objective: To describe the experience of implementing a clinical research site in a tertiary pediatric hospital in Federal District, its challenges and perspectives, always in accordance with the ethical principles that govern research with human beings, established by national and international regulations, with a focus on offering the best therapeutic possibilities available to patients.

Method: The first stage of implementation was the publication of Internal Resolution Nº 177 of June 8, 2020, which provides for the institution of the Clinical Research Site and the regulation for conducting clinical research locally. At this stage, the nucleus composed of a manager and a clinical research analyst was created, and the processes were described through Work Instructions, which would serve as a guide for the performance of all team members. Over time, through training and specific readings, the team gained skills in the analysis of contracts and budgets, and in the configuration of specific software for use in the center, such as the electronic medical record in CRIO Clinicalresearch.io. Nowadays, in addition to all the activities mentioned, the team works with internal audits and control of indicators in order to conduct the stages with quality and under ethical principles.

Results: Since its foundation, prospecting for clinical studies has been active: nineteen feasibility questionnaires were received, from which we were selected to participate in six clinical studies, and at the moment we have patients included in three of these. The main challenge is the effective training of the teams involved, aiming at respecting current resolutions, good clinical practices, and a rate of adherence to clinical protocols above 90%.

Conclusion: Despite being recent, the site is already showing good results, dozens of professionals and interns have been trained, new tools have been implemented, financial return converted into benefits for the institution, and mainly patients benefited by innovative therapeutic alternatives.

Keywords: Clinical Research Protocol. Good Clinical Practice. Ethics.

1. Hospital da Criança de Brasília José Alencar (HCB)

Characterization of inflammatory phenotypes in children and adolescents with severe asthma in the reference outpatient clinic of a University Hospital, and the correlation with clinical and functional control

Stefâni Soares dos Anjos[1]
Carmen Lívia Faria da Silva Martins[1]

Abstract

Introduction: Asthma is a chronic inflammatory disease of the airways or bronchi, caused by inflammation of the airways, being one of the most common chronic diseases that affects both children and adults, and may disappear spontaneously or require treatment. It is clinically manifested by recurrent episodes of wheezing, dyspnea, chest tightness and coughing, especially at night and in the morning. Asthma severity should be assessed after taking control medication for a few months. The severity of the disease is not static and can be minimized over months or years. The study aimed to characterize the inflammatory phenotype of children and adolescents with severe asthma followed at the pediatric pulmonology outpatient clinic of a University Hospital in the Federal District.

Methodology: Observational study with a qualitative and quantitative approach, carried out with a sample of 22 children and adolescents, aged between 3 and 17 years, with severe, difficult to control asthma in the period from September 2021 to September 2022. Data from medical records were analyzed, with complete anamneses used for care, in a specific form of the referred clinic in the first consultation, as well as in the return consultation, after the diagnosis of the disease made by a pediatric pulmonologist. Most patients are still being followed up.

Results: In this study, it was found that the association between eosinophilia and elevated serum IgE is significantly positive (p-value =0.01). Also, it was shown that there are no significant differences between the number of eosinophils and the state of asthma control, either according to Global Initiative for Asthma (GINA) or according to Asthma Control Test (ACT). From a clinical point of view, however, the two phenotypes, eosinophilic asthma and non-eosinophilic asthma, are quite homogeneous, with few differences and a lot of data overlap. It is not possible to establish precisely the differences between them in terms of age, duration of asthma, gender, symptomatology, lung function, and degree of bronchial hyperreactivity. Since in eosinophilic asthma, atopy seems to be more prevalent. Most patients had mild obstructive ventilatory disorder, not responding to bronchodilators.

Discussion/Conclusion: Several authors point out that IgE plays a central role in the pathogenesis of severe asthma. Other studies also indicated that IgE favors the development of bronchial responsiveness in asthmatic patients. Thus, the measurement of IgE levels and eosinophil differential counts are certainly relevant for identifying allergic sensitivity and are important components in the pathophysiology of asthma. Based on this study, it was concluded that the most prevalent phenotypes in the aforementioned outpatient clinic are eosinophilic, atopic, early-onset patients with uncontrolled asthma. It is noteworthy that in monitoring asthma treatment, the drop in the number of eosinophils is positively associated with the improvement in forced expiratory volume in one second (FEV1) and with a good clinical response to corticosteroid therapy. It should be noted, however, that more studies are needed, since not all patients were able to undergo spirometry due to age limitations.

Keywords: Severe asthma. Inflammatory phenotypes. Child. Adolescent.

1. Hospital da Criança de Brasília José Alencar (HCB)

Characterization of patients with bronchiolitis obliterans in a tertiary pediatric hospital

Andressa de Freitas Souza

Abstract

Introduction: Bronchiolitis Obliterans (BO) is a rare respiratory disease that causes damage to the small airways due to the occurrence of chronic inflammation which, if not diagnosed early, results in a serious obstructive disorder with significant impact on the child's quality of life and even leading to death. It is characterized by the presence of granulation tissue in the airways and/or peribronchiolar fibrosis with narrowing of the lumen, causing a cicatricial and obstructive process. Studies have also shown a decrease in cardiometabolic capacity in maximal exercise tests in children with BO, which interferes with daily activities and quality of life. Triggering factors can be chemical, infectious, and immunological. Early diagnosis of BO is extremely important for the best prognosis of the disease. Thus, it is necessary to better understand the risk factors, the specific diagnostic criteria, and the evolutionary aspects of the disease. This research project aims to contribute to a better understanding of the disease by describing the epidemiological profile of patients treated at HCB.

Objective: Characterize the epidemiological, clinical-radiological, and functional profile of patients with bronchiolitis obliterans at the reference outpatient clinic of the *Hospital da Criança de Brasília José Alencar.*

Methodology: This is a cross-sectional observational descriptive study through the search for data in the electronic medical records, according to attendance at the reference outpatient clinic.

Results: Forty-three patients with a previous diagnosis of BO were identified. Males accounted for 55.3% (n=26). The mean age at the time of the study was 9.82 years and the mean age at which the diagnosis was made was 3.67 years old. Regarding the patients' history, 51.1% (n=24) had acute viral bronchiolitis (AVB), 29.8% (n=14) complicated pneumonia, and 12.8% (n=6) organ transplantation, among which 5 underwent bone marrow transplantation, while 1 patient underwent heart transplantation. The evaluation of the chest computed tomography images, 74.5% (n=35), observed a mosaic perfusion pattern, while 55.3% (n=26) presence of bronchiectasis. 10.6% (n=5) of the analyzed patients did not have image information in their medical records. Spirometry showed a predominance of obstructive pattern ventilatory disorder (23.4%) and, regarding the severity of the disorder, there was a predominance of mild obstructive ventilatory disorder (17%), with 8.5% of patients responding to the bronchodilator. 74.5% of patients (n=35) showed good response to inhaled corticosteroids. The average number of hospitalizations was 0.37 and of pulmonary exacerbations 2.32 in the last year.

Conclusion: The present study showed information in line with the literature, such as a slight predominance of BO among male children, with a survival of 6.15 years, acute viral bronchiolitis as the main causal factor, and tomographic images. This fact was not verified with regard to the mild obstructive functional pattern, the good response to inhaled corticosteroids and the low number of hospitalized children, results that are probably due to the early diagnosis of the disease at HCB.

Keywords: Bronchiolitis obliterans. Airway obstruction. Adenovirus. Pediatrics.

Chronic granulomatous disease: epidemiological characteristics of presumed cases attended at a pediatric tertiary hospital

Filipe Gomes Silva[1]
Anna Carolina Silva Dias[2]
Robéria Mendonça de Pontes[2]
Ricardo Camargo[2]
Cláudia França Cavalcante Valente[2]
Fabíola Scancetti Tavares[2]
Karina Mescouto de Melo[2]

Abstract

Introduction: Chronic Granulomatous Disease (CGD) is an Inborn Error of Immunity (IEI) of phagocyte function, caused by mutation in genes encoding Nicotinamide Dinucleotide Phosphate (NADPH) oxidase complex (CYBB, CYBA, NCF1, NCF2, NCF4 and, CYBC1). Patients manifest early in life severe or recurrent infections, mainly in the lung, skin, lymph nodes and liver as well as inflammatory complications in gastrointestinal tract (GIT). Diagnosis is made by dihydrorhodamine (DHR) burst oxidative assay by flow cytometry and genetic sequencing.

Objective: To describe the findings of CGD screening, by DHR assay, in a pediatric hospital in Brazil, and the clinical features of presumed cases.

Methods: A retrospective and prospective study was carried out enrolling children with CGD suspicion, who collected blood sample for DHR assay over the period comprised between September 2021 and July 2022 in a pediatric tertiary hospital in Brazil. Sanger sequencing (genes NCF1 and CYBB) was performed in patients with abnormal DHR assay.

Results: A total of 118 patients were studied, 56% males. The mean age was 4.3 years old (range: 1 month to 17 years old) and 46% of the patients were younger than 2 years old. Pneumonia and abscesses (skin or deep organ) were the main clinical features (18.8 and 17% respectively), followed by gastrointestinal tract disorders (17%) and sepsis (14%). Forty-seven patients (30%) were under antimicrobial prophylaxis with trimethoprim-sulfamethoxazole. High levels (>p97) of IgG and IgM were noted in 34% and 17% of cases, respectively. In total 69 microbiological cultures were collected and 30% of them were positive, with Staphylococcus aureus being the most frequent isolated pathogen (28% of positive cultures). In total 108 (91.5%) DHR assays were normal, six (5%) tests were inconclusive and four (3.4%) had abnormal results. All patients with abnormal DHR test presented pneumonia and/or abscesses as the first clinical feature of CGD and all were receiving continuous antibiotic. Only one had positive culture, with isolation of P. aeruginosa in blood culture. Mutation in NCF1 gene was identified in 2/4 patients and, in both cases, patients were waiting for bone marrow transplantation. The other two patients were not sequenced until the end of the data collection.

Conclusion: CGD is a life-threatening disease, and the prompt diagnosis is crucial for prognosis. This study evidenced the importance of DHR assay in our center, with a relevant frequency of CGD in the evaluated patients.

Keywords: Primary immunodeficiency diseases. Chronic granulomatous disease. Flow cytometry. Pediatrics. Genetic tests.

1. Faculdade Sena Aires
2. Hospital da Criança de Brasília José Alencar (HCB)

Clinical evolution of children and adolescents hospitalized with Severe Acute Respiratory Syndrome due to COVID-19 one year after SARS-CoV-2 infection

Cynthia Lorena de Moura e Araujo[1]
Patricia Antunes da Cunha Ribeiro
Ana Luiza Rosa Diniz
Silvana Augusta Jacarandá de Faria
Sara Habka
Cristiane Feitosa Salviano
Luciana de Freitas Velloso Monte

Abstract

Introduction: The SARS-CoV-2 virus, which causes COVID-19, has become a threat to populations around the world. Little is known so far about the late course of infection in pediatric patients.

Objective: To describe the clinical-functional-radiological evolution of children and adolescents hospitalized with severe acute respiratory syndrome (SARS) caused by SARS-CoV-2 over one year after the acute illness.

Methodology: This is a descriptive, observational, and retrospective cohort study that included patients with COVID-19 caused by the SARS-2, aged 0-18 years, admitted to a referral pediatric hospital, during the pandemic, in the months of July to October 2020. All patients hospitalized with severe acute respiratory syndrome caused by SARS-CoV-2 in the specified period were included in this study. Data was collected from patient records. The study was approved by the Research Ethics Committee (CAAE 31803020.3.0000.0008).

Results: During the study period, July and October 2020, 14.8% (122) of the 823 hospitalized patients had a confirmed diagnosis of SARS-CoV-2 infection. Of those, 19.7% (24/122) had SARS and were included in the study. The age of patients at admission ranged from 0 to 17 years, with a median of 3 years (mean 4.8 years SD ± 6.0), with 54.2% (13/24) being male. Sixteen (66.7%) had chronic diseases. The main signs and symptoms were dyspnea, 95.8% (23), desaturation, 91.7% (22) and fever, 79.2% (19). In the studied sample, 91.7% (22/24) required intensive care unit (ICU) care, five (20.8%) required mechanical ventilation (MV), and six (25%) required non-invasive ventilation. (NIV). Five patients (20.8%) were also diagnosed with MIS-C. None of the patients in this study had persistent symptoms related to COVID-19 for more than 8 weeks after the acute infection. Thirteen patients (56.5%) needed medication for continuous use after discharge, 3 (23.1%) of them exclusively as a result of COVID-19. In this sample of patients with severe acute respiratory syndrome, there was one death attributed to COVID-19 (4.2% case fatality rate in SARS).

Conclusion: The majority of children and adolescents hospitalized for SARS due to SARS-CoV-2 from July to October 2020 in a high complexity pediatric hospital required intensive care and had radiological changes, but progressed satisfactorily over a year, even those who had chronic diseases.

Keywords: SARS-CoV-2. COVID-19. Pediatrics. Clinical evolution. Severe acute respiratory syndrome.

1. Hospital da Criança de Brasília José Alencar (HCB)

Clinical picture of subacute necrosing encephalomyelopathy: a mitochondrial DNA mutation

Luiz Felipe Neves Frazão[1]
Vitória Cordeiro Morais
Gabriel Rodrigues Vargas
Antonio Muniz da Silva Neto
Ana Flávia Espíndola Volpp
Francielle Andrade Carvalho Rosa
Darllen Saluana Ribeiro Peixoto

Abstract

Introduction: Subacute necrotizing encephalomyelopathy (ENS) consists of an extremely rare hereditary neurometabolic pathology, usually present in early childhood, of a severe and progressive nature, with the primary cause being a defect in oxidative phosphorylation and generation of adenosine triphosphate (ATP) in the mitochondria. According to Lopes, et al., 2018, ENS affects 1 in every 40,000 live births, and can lead the patient to death at the age of 7 years, due to pathological symptoms that cause generalized disability to the child's body. Because it is a rare disease, difficult to diagnose and incurable, many patients are not managed efficiently or provided adequate palliative support, contributing to unfortunate prognosis or failed attempts at social integration of these children, disproportionate quality of life, or the basic rights of childhood.

Objective: To understand the main concepts about ENS, regarding its symptoms and palliative supports.

Method: This is a narrative review of the literature, in which the Medical Literature Analysis and Retrieval System Online (MEDLINE) and Scientific Electronic Library Online (SciELO) databases were used, obtaining 678 articles. Of these, 673 works were excluded for inadequacy to the central theme, complete unavailability or for being research funded by pharmaceutical industries. Five articles in English, Spanish and Portuguese published between 2008 and 2022 were selected. The descriptors in Health Sciences (DeCS) were used: Metabolic Diseases Mitochondria Mutation Palliative Support Therapy.

Results: The research showed that the evolution of ENS is insidious and progressive, with minimal curative prospects, a fact emphasized in the literature. Since mitochondria are responsible for the synthesis of cellular energy, in the form of ATP, a pathogenic mutation in its deoxyribonucleic acid (DNA) can easily cause structural complications in any organ, but tissues with greater oxygen demands are harmed, such as skeletal tissue. The pathological clinical picture is characterized in children aged less than one year old, with signs of subacute occurrence, manifested as anorexia, loss of head control, seizures, intellectual regression and recurrent respiratory disorders. As it is a neurometabolic disease with no cure, the treatment is based on multidisciplinary palliative support therapies, mainly in endocrine control, occupational physiotherapy, and detection of cases of hypoxia. However, the delay in diagnosis or wrong management without scientific basis, may cause deterioration of patients' physical and psychological health.

Conclusion: In view of the precarious amount of scientific research on ENS, in addition to the lack of specific therapies with scientific foundations, palliative multidisciplinary follow-up is the best option to avoid worse prognosis for patients. Requiring early interventions, government screening measures can prevent possible conditions and worsening of progressive symptoms, in addition to encouraging studies about the disease and correct management, to prevent the growing mortality rate.

Keywords: Metabolic diseases. Mitochondria. Mutation. Palliative support therapy.

1. Universidade de Rio Verde

Clinical-epidemiological aspects and evaluation of the survival of children over 18 months with neuroblastoma: 9 years' experience at a Brazilian institution

Samara Nidale Karaja[1]
Flávia Delgado Martins[2]

Abstract

Introduction: Neuroblastoma is the most prevalent solid extracranial tumor in children. Given the broad spectrum of disease presentation and prognosis, it is understood that correct staging and risk stratification are extremely important for determining therapy.

Methodology: Observational, analytical, longitudinal, and retrospective study. Data were collected from patients aged 18 months or older, diagnosed with neuroblastoma admitted to the Hospital da Criança de Brasília José Alencar between 01/2011 and 02/2021. The main objective was to describe the epidemiological and clinical characteristics of this sample.

Results: 30 patients were recruited, 20 aged between 18 and 69 months. The most frequent location was the abdomen, and most patients were evaluated for planned factors.

Conclusion: The cohort had characteristics similar to those described in the literature, both in terms of clinical and epidemiological characteristics, response to therapy, Overall Survival (OS), and Event Free Survival (EFS) for patients with the same planned factors (> 60 months, presence of distant metastases). BMT (bone marrow transplant) in the first proven treatment increased SLE. Patients with more advanced age at diagnosis, older than 60 months, seemed to have an indolent disease, but little chemosensitivity.

Keywords: Neuroblastoma. Prognosis. Survival.

1. Centro Universitário de Brasília (CEUB)

2. Hospital da Criança de Brasília José de Alencar (HCB)

Comprehensive care for people with leukodystrophy in the unified health system

Raissa Silva Frota[1]
Amanda Oliva Spaziani
Vitória Pereira Reis
Thiago Figueiredo de Castro

Abstract

Introduction: Comprehensive care for people with rare diseases in the unified health system is a topic that has been gaining visibility, as well as the access to healthcare and its technologies, so much so that in 2014 a compilation of guidelines was prepared to protect this group and ensure they get cared for. Brazil has difficulties in guaranteeing healthcare and comprehensiveness for this population, either because of the country's diversity and geographic dimension, or because of institutionalized public policy issues. When it comes to rare diseases, which are not always visible due to their low prevalence in the population, they often encounter more obstacles and difficulties for the diagnosis, treatment and other measures that provide quality of life for the affected individuals and their support network. An example that we can mention of a pathology that faces all these biases is leukodystrophy, a group of more than 30 genetic diseases caused by defects in the synthesis or metabolism of myelin that lead to hypomyelination, with a prevalence of 1:40,000 to 1:160,000 live births.

Objective: This study aims to address comprehensive care for people with leukodystrophy in the unified health system, specifically in smaller cities, with general low income and little access to information/education.

Method: This is a literature review about comprehensive care for people with leukodystrophy as a basis for an experience report of clinical management of a patient diagnosed with leukodystrophy and its consequences. For the literature review, the PubMed database was used with the descriptors rare diseases, leukodystrophy and comprehensive care.

Results: Of the 183,283 results obtained on the PubMed platform, the following studies were used as exclusion criteria: no comprehensive care for rare diseases outside the 5-year period, and those that do not deal with leukodystrophy, which left 34 studies for review. Most cases had a late diagnosis, which at the beginning of the disease had subjective symptoms, and even when going through several specialists, the referral to the neurologist and/or geneticist was not properly carried out, and when carried out, it occurred late. The diagnostic situation and survival conditions narrow when it comes to more remote regions of the country, where lack of access to information both by the family and by health professionals are significant obstacles to the diagnosis, affecting the therapeutic, corroborating early deaths, and emphasizing the lack of human and material resources of the institutions in which the patient is hospitalized.

Conclusion: Based on the cases discussed, it can be noticed that the establishment of references for care and protection for users and their support networks, the production of matrix support in the care network, the difficulty in tracing unique therapeutic projects, multidisciplinary assessments based on devices and assistive technologies in order to provide autonomy, especially with regard to leukodystrophy are needed for this pathology that does not have a flowchart to conduct cases in the Unified Health System.

Keywords: Leukodystrophy. Matrix support. Primary care.

1. FEPECS

Cost analysis of importing drugs for hematopoietic stem cell transplant in a high-complexity pediatric service

Anna Beatriz Gomes da Silva[1]
Adriele Alves Santos[1]
Igor Alves Mota de Lima[1]
Rafael de Souza Martinez[1]
Kalina Kelly Alves Ribeiro[1]
Leandro Pereira Bias Machado[1]

Abstract

Introduction: Hematopoietic stem cell transplant (HSCT) is a treatment for diseases that affect the blood cells, such as leukemias and lymphomas. It consists of replacing diseased bone marrow cells by healthy ones. Currently, due to the unavailability in the national market, it is necessary to exceptionally import some of the drugs used in HCST.

Objective: To identify the drugs and costs of the import process due to exceptional circumstances for single patients in the HSCT service.

Method: This is a descriptive survey of the import data that occurred between August 2019 and October 2022, in a high-complexity pediatric service in the Midwest. Data were collected through verification of invoices related to the importation of products for individuals, inserted in the MV Soul® system.

Results: 16 exceptional import processes were initiated for the following drugs: THIOTEPA, CARMUSTINE and MELPHALAN, totaling 115 imported vials. Of these vials, 83.5% were Thiotepa (n=96), with an average delivery time of 74 days, 4.3% were Carmustine (n=5), with an average delivery time of 107 days, and 12.2% Melphalan (n=14), with an average delivery time of 89 days. The total value of the 16 import processes opened for HSCT patients was R$ 895,076.85. When this amount is detailed, we identify that R$ 677,462.50 were spent on medicines, approximately 75% of the total; fees and service of the import process (taxes, air and land transport, forwarding agent, advisory) an amount of R$ 217,614.35 was disbursed, 25% of the total. The most expensive product of those analyzed was Thiotepa, which had a total cost of R$ 777,132.12, accumulating approximately 86% of all import expenses and with an average price per vial of R$ 8,095.12. Melphalan and Carmustine were imported at a time of rupture in the national manufacturing of these drugs, which allows a cost analysis to be carried out between the costs of the imported and the national process. Nationally, for Melphalan, purchases were made for a total of 123 vials, each with an average value of R$ 157.52. As for those purchased outside Brazil, 14 vials were imported, each having an average value of R$ 1,640.05 – that is, a cost 941% higher when compared to domestic purchases. In the case of Carmustine, the average price for its domestic acquisition was R$ 286.44 and for international acquisition, it was R$ 18,991.70 (taking into account all taxes and service fees) an increase of approximately 6530%.

Conclusion: The costs of importing the analyzed drugs exceeded R$ 890,000 with 25% of this amount only for payment of fees and services. Considering the fact that these drugs are essential in treatment protocols for HSCT, combined with the long time to complete the import process per patient and the high costs observed in this study, it is necessary to propose alternatives for importation on an exceptional basis. In addition to the national production of these products, the discussion about the possibility of importation through a legal entity is essential and studies on the feasibility of this process are extremely necessary.

Keywords: Importation of products. Thiotepa. Melphalan. Carmustine. Process assessment

1. Hospital da Criança de Brasília José de Alencar (HCB)

Databases and their importance for the treatment of congenital heart diseases in children: an analysis of pediatric intensive care

Helena Monte Varandas[1]
Ana Beatriz Caetano Santos de Sá
Ana Clara Monte Varandas
Ana Clara Moreira Almeida
Beatriz Eler de Lima
Caio Toscano Lessa
Pedro Augusto Goncalves dos Santos

Abstract

Introduction: Congenital heart diseases are complex disorders that can be caused by genetic factors and can affect children, leading to abnormalities in the heart's structure or function. Mostly, these diseases require lifelong treatment and care. With globalization, databases emerged as crucial tools in treating congenital heart diseases. They help the development of knowledge about pediatric treatment and the registration of surgical outcomes worldwide. The Virtual Pediatric Intensive Care Unit Performance System (VPS), ANZ Congenital Outcomes Registry for Surgery (ANZCORS), and other databases play an essential role in improving human care through technological development and data integration in Medicine around the globe.

Objective: This review aims to analyze the importance of databases in providing a new perspective on the treatment of pediatric congenital heart diseases, enabling more accurate and dynamic information in the field. Furthermore, it intends to highlight the changes arising from technological breakthroughs and the integration of medical discoveries and studies globally.

Methods: On March 11th, 2023, a review was conducted using PubMed with the following keywords: 'congenital heart disease', 'intensive care', 'cardiac', 'pediatric', 'database', and 'surgical outcomes'. It was filtered to include 'reviews" and 'full text', resulting in 25 articles identified. After content analysis, 4 were selected for their relevance to the theme, as they mentioned not only database examples, but also their direct connection with congenital cardiac diseases.

Results: The use of databases has significantly improved the quality of care for patients with cardiac diseases. For example, the Pediatric Intensive Care Audit Network collects specific data on children's disease treatment in the UK's National Health Service. It provides medical supervision, reviews, monitors treatment outcomes, provides epidemiological data, controls supply and demand, and can develop a healthcare plan, all of which could improve care for cardiopathic disease. Another is the VPS database, in the United States, which allows participants to collect information on diagnoses, illness severity, research studies, and other data. It has improved knowledge of a child's clinical condition as a whole. Besides, ANZCORS was established in Australia and New Zealand in 2017. It helped the analysis of pediatric cardiac surgery data, which reflected a low overall mortality. Specifically, 9,793 procedures were performed, of which 33% were on children aged 29 days to 1 year, and the result was no huge post-operative complications, mostly. Therefore, health quality in patients' lives is already being significantly improved with databases, considering ongoing projects. The differentiated care of children with those systems enhances the chances of living better with complex disorders, which was not possible a few decades ago.

Conclusion: The quality of pediatric cardiac surgery will be boosted with the insights coming from global technology. Thus, distinct countries may have access to data from other locations and new techniques can be shared. Finally, congenital cardiac diseases are gaining new possibilities of treatment and monitoring by using databases.

Keywords: Cardiac. Congenital heart disease. Database. Intensive care. Pediatric. Surgical outcomes.

1. Universidade de Brasília (UnB)

Description of the epidemiological profile of down syndrome in Brazil between 2010 and 2020

Pâmella Carneiro da Cruz

Abstract

Introduction: Down syndrome (DS) is a genetic disease resulting from trisomy of chromosome 21, which occurs due to the failure of chromosome 21 separation during gametogenesis, leading to an extra chromosome. It is the fourth most common congenital anomaly in Brazil but data about DS is underreported in the health information systems.

Objective: To describe the epidemiological profile of DS in Brazil between 2010 and 2020.

Methods: This is a retrospective ecological study that used public databases from the Department of the Unified Health System (DATASUS) to filter data on maternal profile, gestational and perinatal periods from 2010 to 2020. The bank surveyed was Live Birth Information Systems with information from the Certificate of Live Births provided by DATASUS, using the Tabnet system.

Results: In this period 10.775 cases occurred with a mean of 980 cases per year. Regarding geographical regions, the southeast had 5.093 cases (47%) followed by the northeast with 2.394 cases (22%), the south with 2.035 cases (18%), the north with 773 cases (7%) and the with 480 cases (4%). The most described place of registration was the hospital with 2.735 cases (25.8%). However, 7.992 cases (74%) were not informed or were ignored. The most significant maternal age groups were among 20 to 34 years old with 1.095 cases (10%) and between 35 to 39 years with 742 cases (6.8%), but 74% were not registered. Also, data about the maternal level of education was absent. The prenatal care appointments were not informed in 74% of cases. 7 or more appointments occurred in 1.800 cases (16%), 4-6 in 705 cases (6,5%), 1-3 in 189 cases (1,7%) and 70 cases (0,6%) didn´t have an appointment. Concerning the weeks of gestation, 7.889 cases (73%) had 37-41 weeks and 2.388 cases (22%) had 32-36 weeks totalizing 95% of the cases. According to the type of pregnancy, 10.580 (98%) was a single pregnancy followed by 175 cases (1,6%) of twins and 4 cases (0,03%) of triplets' twin pregnancy. Representing 64%, with 6.917 cases, cesarean sections were performed, followed by 35% of vaginal deliveries. Among the newborns, the female gender was the most frequent with 1.474 cases (52,9%) and 1.312 cases (47%) were male. The newborns had white skin color in 5.255 cases (48,8%), brown skin color in 4.615 cases (42,8%) and black skin color 483 cases (4,48%). The database didn´t have information about the Apgar or weight of the newborns with DS.

Conclusion: The southeast region had most cases. The place of registration, maternal age and quantity of prenatal care appointments didn´t have enough data. Generally, they were a single, term or full-term pregnancy, with cesarean section delivery. Most cases were female and white skin-colored newborns. The underreported events and the variance in the standard of information filled out about DS in the Certificate of Live Births and entered into the system limited the description

Keywords: Congenital abnormalities. Down syndrome. Health information systems. Vital statistics. Epidemiology.

Description of the implementation process of liposomal Amphotericin B supply by the Ministry of Health in a pediatric hospital in the Midwest

Cleia Ribeiro da Silva[1]
Celyne dos Santos Teixeira[1]
Nara Marinho de Lima[1]
Nayara Rodrigues Mota[1]
Adriele Alves Santos[1]
Jean Vinicius O Campo[1]
Letícia da Costa Lima de Oliveira[1]

Abstract

Introduction: Systemic fungal infections have had an increased incidence over the last few years, especially in immunosuppressed pediatric patients, being identified as one of the main causes of morbidity and mortality among this population. One of the drugs used as a line of treatment for systemic fungal infections is liposomal amphotericin B (L-AmB), a broad-spectrum antifungal that is currently available from the Ministry of Health (MH). The availability of this drug is regulated by Ordinance SCTIE/MS No. 57, of July 12, 2022, for the treatment of rhino-orbito-cerebral mucormycosis. This initiative aims to expand the therapeutic set for mucormycosis and improve assistance to national health service users in Brazil.

Objectives: To describe the process of supplying L-AmB by the MH in a pediatric hospital and raise potential savings generated by the centralization process.

Methods: This is an experience report on the process of analysis, planning and implementation of the centralized supply of L-AmB in a public, pediatric and tertiary hospital in the Federal District, based on the flows established by the Technical Surveillance Group and Control of Systemic Mycoses of the MH. Potential savings were evaluated through the registration of invoice entries, originating from MH, in the period from December 2022 to January 2023.

Results: In the planning stage, a flowchart was constructed with the details of the internal process for obtaining L-AmB, which begins with the identification of the physician's need to use the medication. Subsequently, the hospital Infection Control Service assesses compliance with the protocol criteria and, if so, forms a list of necessary documents. The clinical pharmacy service analyzes the conformity of the medication request, forwarding it to the MH. After approval of the process, the drug is made available with an expected arrival time of 3 working days. Receipt is checked by the Pharmaceutical Supply Center, sent to the hospital pharmacy and finally distributed for administration to the patient. In the analyzed period, an invoice was identified from the centralized distribution of the MH, where 80 bottles were provided. Centralization generated savings for the national health service of R$46,640.00 in this treatment. This fact is due to the comparison of centralized (R$583.00) and decentralized (R$1,552.00) acquisition prices, where there was a 62% reduction in the unit cost of the product. It is inferred that the reduction in value is due to the concentration of purchase, bargaining power with the supplier and the direct purchase format from the manufacturer, avoiding intermediaries.

Conclusion: The L-AmB implantation process allowed the centralization of acquisition by MH, maintaining the same efficiency. The quality of care was maintained by managing resources, solving latent needs and optimizing processes, especially in cases of invasive fungal infections.

Keywords: Amphotericin B. Fungal infections. Pharmacoeconomics. Hospitals. Pediatric.

1. Hospital da Criança de Brasília José Alencar (HCB)

Development of technology for early confirmation of sickle cell disease and other hemoglobinopathies in the context of neonatal screening

Larissa Lemos Mendanha Cavalcante[1]
Isis Maria Quezado Soares Magalhães[1]
Ricardo Camargo[1]
José Carlos Martins Córdoba[1]
Natalia da Silva e Lamas Mendes[1]
Marina da Costa Ribeiro[1]
Agenor de Castro dos Santos Moreira Júnior[1]

Abstract

Introduction: Hemoglobinopathies are monogenic diseases caused by genetic disorders of hemoglobin and represent the most common causes of global morbidity and mortality. Presymptomatic diagnosis of hemoglobinopathies, especially the more severe forms, requires more sensitive methods and is essential for adequate treatment. Preventive measures and early therapeutic interventions have provided better quality of life and increased survival. Due to the diagnostic difficulty in newborns, and in the light of recent scientific advances, this study proposes to carry out the early molecular diagnosis of hemoglobinopathies in the Federal District, aiming to expand the spectrum, precision, and reliability of the results neonatal screening.

Objective: To develop and implement molecular analysis protocols for the detection of hemoglobinopathies in children and adolescents treated at the public health service in the Federal District, in addition to an epidemiological study in the population in question.

Method: A retrospective-prospective descriptive cross-sectional study was carried out. All pediatric cases, between 0 and 18 years of age with suspected hemoglobinopathies, admitted between 2018 and 2022 by the Neonatal Screening Program of the Federal District and those attended at the hematology outpatient clinic of the Hospital da Criança in Brasília, were part of the sample. Molecular tests were performed using methods based on PCR, Sanger genetic sequencing and MLPA (Multiplex Ligation-dependent Probe Amplification). The descriptive epidemiological study was obtained by the frequency of mutations and distribution of hemoglobinopathies and variant hemoglobin found from global data from neonatal screening in the DF and genetic-molecular data obtained from this study.

Results: Molecular alterations typical of hemoglobinopathies were identified in 232 children. Of these, 101 cases presented some variant hemoglobin (43.53%), 88 presented alterations of –thalassemia (37.93%), 40 of thalassemia (17.24%) and in 3 cases (1.29%) hereditary persistence of fetal hemoglobin (PHHF types 1 and 2) was detected. The most common deletional mutation in alpha thalassemia was $-\alpha^{3.7}$ present in 42 cases (47.73%). The HBB: c.92+6T>C beta mutation in heterozygosis was the most frequent, being detected in 4 individuals (10.3%). The most prevalent variant was heterozygous HbS (52 patients – 51.49%), followed by heterozygous HbC, present in 9 individuals (8.91% of carrier cases).

Conclusion: The main objective of the study was achieved, since it was possible to implement molecular techniques that showed diagnostic resolution, within an algorithm that includes the rational use of resources, in order to optimize SUS investments. With the establishment of molecular biology methods, it is possible to carry out the coverage and accuracy of the confirmatory diagnosis in the pre-symptomatic phase of the disease, that is, from neonatal age, allowing clinical intervention in anticipation of possible deleterious manifestations. Mutations with important clinical and prognostic impact related to alpha and beta thalassemia were detected, in addition to variants never described in databases. The data found in this study shows an expressive variability of hemoglobin and a great racial diversity present in individuals born in the Federal District and surroundings, being considered a heterogeneous population made up of individuals from different Brazilian regions, with African, Asian, Italian, Amerindian, Spanish and Portuguese descent.

Keywords: Hemoglobinopathies. Sickle cell disease. Thalassemia. Neonatal screening. Molecular diagnosis.

1. Hospital da Criança de Brasília José Alencar (HCB)

Distance-learning course saving lives: a strategy for early diagnosis of child and youth cancer

Sandra Emília Almeida Prazeres[1]
Anice Holanda Nunes Maia
Patrick da Silva Camêlo
Jackson Matos de Sousa
Juvemar Rodrigues dos Anjos Júnior

Abstract

Introduction: in Brazil, child and youth cancer stands for the first cause of death between the ages of zero and nineteen years old, secondary prevention being the most effective strategy to increase healing chances. Early diagnosis of child and youth cancer (EDCYC) decreases the gap between first symptoms and beginning of treatment, however it depends on effective acting of primary and secondary health-oriented teams, which must be trained to do that. Non-governmental organizations (NGO) play an expressive role on this front, and some are part of a multidisciplinary effort to train healthcare professionals on that theme.

Goal: To present a distance course on EDCYC organized by Associação Peter Pan (APP), an NGO from the state of Ceará which works to increase healing rates and improve life quality of children and teenagers with cancer.

Method: It is an experience report, a method consisting of professional and scientific interventions in academic fashion. Partial results of Distance-learning Saving Lives from March through December 2022 are reported, having an indefinite availability period. Information was collected through reports provided by Moodle software.

Results: Distance-learning Saving Lives course was selected by the National Confederation of Support and Assistance Institutions for Children and Teenagers with Cancer, for its theme relevance and potential reach. Training, focused on healthcare and education professionals, has two levels of complexity: medium and superior, both of them containing 09 modules that approach public policies of child and youth cancer prevention and control, signals and symptoms, procedures for early diagnosis, and patient reference and counter-reference system, all of them voluntarily developed by professionals with expertise in oncopediatrics. In the available 10 months, the course has 1.367 subscribers, 510 (23,70%) at medium level and 857 (76,30%) of upper-level professionals. As for the participants" occupations, 740 (54,13%) are healthcare community agents (12,51%), nursing technicians (13,68%), nurses (19,24%), and doctors (8,71%), relevant players for early diagnosis in places where they work. 45,87% are social workers, dentists, nutritionists, and psychologists. 32,70% correspond to people from the community interested in knowing and disseminating the subject. The students came from 20 states and the Federal District, covering 78% of federative units. The course has a 23.70% of graduates and has a partnership with the state of Ceará permanent education system for positive evolution in the number of graduates.

Conclusion: Good receptivity was noticed at the national level, and the majority of participants are professionals with higher education from the areas that make up the teams of the family health strategy, and expanded family health centers, units committed to the early detection of diseases. Also noteworthy is the role of the community health agent, who is the link between the community and the professional teams. Therefore, training these professionals represents the possibility of reducing the time between the first signs and symptoms of childhood cancer and the start of treatment**.**

Keywords: Neoplasms. Early diagnosis. Education continuing.

1. Associação Peter Pan

Early stimulation strategies for children aged 0 to 3 years old with cerebral palsy: overview of systematic reviews.

Priscilla Lemos Gomes[1]
Aurelio Matos Andrade[1]
Juliana da Motta Girardi[1]
Valdenize Tiziani[1]
Flavia Tavares Silva Elias[1]
Indyara de Araujo Morais[1]

Abstract

Introduction: Cerebral palsy (CP) comprises a spectrum of permanent neurological alterations that compromise motor activity and posture, leading to functional limitations caused by non-progressive lesions that occur in the developing fetal or infant brain, in the pre–, peri– or postnatal period. In Brazil, the prevalence of CP found was 1.37/1,000 CP live births in the city of Aracaju. It is noticed, however, that the distribution of prevalence in urban areas is not homogeneous, being 4 times more frequent in the low-income periphery. Considering the neurotypical development milestones, it is necessary to stimulate children to expand their skills through strategies that promote cervical control, rolling over, dragging, sitting, crawling, standing and walking, in addition to communication, socialization, manipulation and exploration of objects and space, attending to guidelines and care for each stage of development of the child.

Objective: To identify the different strategies of early stimulation adopted in health and education services in the care of children with cerebral palsy from 0 to 3 years in the world, involving families, health services, schools, community and support from the social protection network.

Method: This is an Overview of systematic reviews, structured on Prisma assumptions with registration in PROSPERO CRD42020185596. The research was carried out based on the electronic and systematic search of articles indexed in the databases: PubMed via MedLine, EMBASE, Health Systems Evidence, Center for Reviews and Dissemination (CRD), PDQ Evidence, Cochrane Library and Effective Health Care Research Consortium (EHCRC), in July 2022.

Results: Considering the established criteria, 11 systematic reviews were included in the study that showed the following early interventions aggregated in the studies: Goals, Activities and Motor Enrichment Program (GAME), functional physiotherapy, treadmill gait training, Neurological Development Therapy (NDT), intramuscular injections of BoNT-A (botulinum toxin A) associated with Occupational Therapy Curriculum and Monitoring System (CAMS), and training of parents and guardians for the practice of early intervention. Among the studies, 63.6% of the early interventions focused on motor function domains and skills. The application of the intervention should consider the assessment of the uniqueness of each child to indicate the best early intervention strategy.

Conclusion: It was observed that care practices for children with CP aged 0 to 3 years need to be strengthened in the networks of health, education and social care professionals in public and private services, with the participation of family members and caregivers. It was observed that an integrated approach with the implementation of a multiple line of care helps children with CP to obtain better functional gains and improve their quality of life.

Keywords: Cerebral palsy. Early medical intervention. Child development. Systematic review.

1. Hospital da Criança de Brasília José Alencar (HCB)

Edwards Syndrome: performance of speech therapy and physiotherapy helping in survival with quality of life and functionality

Juliana Cristina Gonçalves de Menezes[1]
Flavia Martins Gervasio
Helen Abdala Carvalho
Rafaela Campos Ferreira

Abstract

Introduction: Edwards Syndrome is the second most common genetic alteration in newborns and is characterized by having three chromosomes in the 18th pair. It presents several malformations, mainly cardiac, orthopedic, neurological, and pulmonary alterations, affecting mainly female fetuses, with poor prognosis, with a percentage of only 10% of patients alive after the first year of life. Due to the complexity of the physiological and anatomical changes, patients need care support by an integrated multidisciplinary team capable of providing healthcare with attention to the family network.

Objective: To describe a clinical case, a child with Edwards Syndrome, based on the synchronic performance of Speech Therapy and Physiotherapy centered on the family, with increased life expectancy and motor and feeding gains.

Method: Female patient, three years old, with Edwards Syndrome, 30 weeks premature, diagnosed prenatally with fetal ultrasonography and evaluation of human chorionic gonadotropin, alpha-fetoprotein and unconjugated estriol in maternal serum. At the beginning of the rehabilitation, she presented congenital heart diseases: intraventricular communication of a large peri membranous inlet, patent ductus arteriosus of small size and bandage; pulmonary alteration with signs of severe stenosis, cerebral dysfunction, global hypotonia and musculoskeletal alterations, with long fingers and poorly developed thumb, muscle weakness, dietary alterations with emphasis on severe dysphagia and significant food refusal.

Results: The patient started speech therapy in conjunction with physiotherapy at the age of 2 years and 5 months, showing significant neurodevelopmental delay, equivalent to a child aged 4 to 5 months, deficit in cervical control, precarious trunk control and no reactions as posterior, lateral and anterior protection. Difficulty with hand-to-mouth connection, sensory changes, poor midline reach. Currently 3 years and 7 months old, after 18 months of intervention, five times a week and periodically with a pediatrician and neurologist, she managed to reach the necessary milestones for safe, pleasant and responsive feeding. Handles food and safely reaches the mouth, always accompanied by the family. She is able to sit, with good cervical and trunk control. In joint physiotherapy and speech therapy sessions, emphasis was placed on oral and global motor skills, breathing exercises, Gett Approaches Permission Approach / Soffi Method for feeding fragile babies and Dir Floortime Method, always thinking about the good relationship between child, family and therapist, seeking evolution and respecting individual differences.

Conclusion: The Edwards Syndrome paradigm is one of short survival and limited functionality. Timely intervention associated with family-centered care, based on an interdisciplinary view of Speech Therapy and Physiotherapy, can offer scientific information that offers professionals and families a new perspective on survival, gains in motor development and pleasure in eating.

Keywords: Edwards Syndrome. Physiotherapy. Speech therapy. Congenic cardiopathies. Rehabilitation. Eating disorder.

1. Desenvolva Espaço Terapêutico

Epidemiology of B-others molecular markers of precursor B-Cell pediatric leukemia

Beatriz Canovas Feijó Oliveira[1]
Ricardo Camargo[2]
Lucas Caetano Melo

Abstract

Introduction: The classification of leukemias considers both the genotype (mainly in relation to the founding mutation) and the gene expression profile. The molecular biology of B-cell Acute Lymphoid Leukemia (ALL) may vary greatly and is divided into two large groups: recurrent B-ALL and B-other ALL. The latter encompasses a diverse set of apparently less frequent, but relevant genotypes, which were not detected before, due to the lack of diagnostic tools. The B-others are a very heterogeneous group, within which there are different subgroups with distinct gene expressions.

Objective: To describe the epidemiological profile of typical molecular markers of the B-others group, identifying alterations in the following genes: CRLF2, JAK1, JAK2, FLT3, IKZF1, PAX5, BTG, ETV6, CDKN2A/B, RB1, ERG, and iAMP21.

Methods: This is a descriptive, cross-sectional, and retrospective study, with data analysis from medical records and data obtained at the Translational Research Laboratory of the Children's Hospital of Brasília (HCB – Hospital da Criança de Brasília José Alencar), from January 2016 to December 2020. The MLPA technique (Multiplex ligation-dependent probe amplification) was used to detect deletions and duplications in the following genes: CRLF2, JAK1, JAK2, FLT3, IKZF1, PAX5, BTG, ETV6, CDKN2A/B, RB1, ERG, and iAMP21.

Results: Throughout the study, 173 medical records of patients diagnosed with ALL-B at HCB from 2016 to 2020 were analyzed. After excluding recurrent translocations (BCR/ABL, ETV6/RUNX1, TCF3/PBX1 and KMT2A/AFF1), 53.3% (n=94) were classified as B-others. In the context of B-others differentiation, 65 patients had at least one of the mutations in the researched genes. The frequency of each gene alteration was as follows: 28.2% CDKN2A/B (n=28) 21.15% IKZF1 (n=21) 20.14% PAX5 (n=20) 17.12% CRLF2 overexpressed (n=17) 8.5% CRLF2 rearranged? P2RY8-CRLF2 fusion? (n=8) 10.7% ETV6 (n=10) 10.7% RB1 (n=10) 8.6% BTG (n=8) 7.5% ERG (n=7) 6.4% FLT3 (n=6) 4.3% iAMP21 (n=4) 2.1% JAK2 (n=2) 0.7% JAK1 (n=1). It is noteworthy that this is the frequency of every single mutation, and the same patient may have more than one mutated gene. In regard to mutations identified in the FLT3 gene, one of them is of the FLT3-ITD type, two are FLT3del and three are FLT3-TKD. In addition, concerning mutations detected in the IKZF1 gene, all of them occurred as deletions in heterozygosity.

Conclusion: A greater frequency of B-others mutations was found in comparison to literature. This finding highlights the importance of the articulation between laboratory and clinical staff, as well as the relevance of molecular differentiation in determining prognosis, risk stratification, and individualized therapeutic management, considering the possibility of targeted therapy.

Keywords: Acute lymphoid leukemia. B-others molecular marker.

1. Universidade Católica de Brasília (UCB)

2. Hospital da Criança de Brasília José Alencar (HCB)

Clinical epidemiological study of children and adolescents with severe SARS-CoV-2 infection admitted to the intensive care unit at a tertiary pediatric hospital in the Federal District

Patricia Antunes da Cunha Ribeiro[1]
Cynthia Lorena de Moura e Araujo[1]
Selma Kawahara[1]
Cristiane Feitosa Salviano[1]
Hevelin Silveira e Silva[1]
Valdenize Tiziani[1]
Luciana de Freitas Velloso Monte[1]

Abstract

Introduction: COVID-19 caused a collapse in healthcare systems worldwide and, despite many studies addressing the issue, many aspects surrounding SARS-CoV-2 infection remain unclear. Even though COVID-19 is manifested as a mild infection in most children, a small proportion develops a severe illness requiring ICU admission and potentially leading to fatal outcomes.

Aim: Map the clinical and epidemiological profile of patients aged 0-18 years admitted to the ICU of a tertiary pediatric hospital in the DF region, during the onset of the COVID-19 pandemic.

Methodology: This is a clinical-epidemiological descriptive cross-sectional study. The inclusion criteria consisted of patients aged 0-18 years admitted to the ICU of a reference hospital in the DF region between July and October 2020 with severe or critical SARS-CoV-2 infection. Infectious etiology in the diagnosis of coronavirus in all patients was confirmed either by molecular or clinical-epidemiological-serological criteria. The study was approved by the Ethics and Research Committee. Data collection used information obtained from electronic patient records utilizing a specific form designed for this study on the REDCap application. Information collected included socio-demographic data, medical history, signs and symptoms, complementary investigations, diagnostic test results for the detection of SARS-CoV-2, treatment, management and outcome. Statistical analysis used categorical variables describes as frequencies and percentages, and continuous variables described as average, median, standard deviation and inter-quartile ranges (IQRs).

Results and discussion: During the period studied, 122 (14.8%) patients had been infected by SARS-CoV-2. Thirty-nine (32%) were admitted with SARS-CoV-2 infection and went on to develop severe or critical illness, needing admission to ICU, which is consistent with the findings of Preston et al (2021), Kim et al (2020) and Nachega et al (2022). More than half of the children assessed received a diagnosis of SARS (56.4%) and 33.3% received a diagnosis of MIS-C. A Brazilian multicentre study of patients with severe illness found a similar percentage of patients with SARS, but MIS-C represented only 13% of the cases reported (PRATA-BARBOSA et al, 2020). A median age of 5 years old was found to be consistent with many published studies (NACHEGA et al, 2022; ESPOSITO et al, 2021; OLIVEIRA et al, 2021). There was a slight predominance of female patients, which is compatible with the findings of an African study undertaken by Nachega et al (2022) and the recent meta-analysis by Toba et al (2021). Frequently, comorbidities have been associated to a worse prognosis in COVID-19 in children; however, in this study, a lower percentage of patients with associated comorbidities (48.7%) was observed; similar findings were reported by authors Prata-Barbosa et al (2020) and an American study, Kim et al (2020). The most common symptoms were fever, dyspnea and cough, all of which were also reported by other authors, such as Nachega et al (2022), Götzinger et al (2020), Prata-Barbosa et al (2020), Oliveira et al (2021) and Lee et al (2022). Patients with MIS-C presented less frequently with respiratory distress and hypoxemia, despite presenting more frequently with fever, gastrointestinal and skin symptoms, dehydration, shock and sepsis. A multicentered study conducted in Spain by García-Salido et al (2020) found similar results. The majority of patient in this study had previous history of contact with a suspected case, mainly at home, which is a similar finding to those of other studies (WURZEL et al, 2021). A viral panel used for molecular detection of other respiratory viruses was undertaken in approximately 30% of patients. SARS-CoV-2 was detected alongside other viruses in approximately 18% of patients tested, which is concurrent with a study by Prata-Barbosa et al (2020). The most frequent radiological finding was pulmonary consolidation, present in almost half the cases studied and compatible with the study by Kim et al (2020). Differently from most studies which found ground-glass opacification as the most prominent finding in chest CT, in this study consolidation and pleural effusion

1. Hospital da Criança de Brasília José Alencar (HCB)

were predominant (KIM et al, 2020; TOBA et al, 2021). Among patients with MIS-C who underwent an echocardiogram at onset of symptoms (11/13), 81.8% presented signs of impaired cardiac function, even if mild. Coronary involvement was seen in only 11.1& of cases. These findings are corroborated by the study undertaken by Feldstein et al (2020). Regarding management, almost 70% of patients in this study needed oxygen therapy (more than 95% in the SARS group) and almost 45% of those needed invasive mechanical ventilation. These averages were higher than those reported by multi-center cohort studies undertaken by Götzinger et al (2020) in Europe and Bailey et al (2021) in the United States. However, these studies also included data from mild cases, such as those that did not required hospitalization and even asymptomatic cases. In this study, when groups were analyzed separately, SARS patients were more likely to receive oxygen, whereas MIS-C patients were more likely to need mechanical ventilation, proportionately due to higher propensity to shock and sepsis. The average time on mechanical ventilation was 6 days, similar to that reported in other studies, such as Götzinger et al (2020), Prata-Barbosa et al (2020) and Shekerdemian et al (2020). Therapy support utilized by patients assessed was similar to that recommended by current guidelines. Corticosteroids were administered in 73.2% of cases, and 90.2% of patients were prescribed antibiotics. 100% of patients with MIS-C received both corticoids and antibiotics. Oseltamivir, an antiviral medication used to treat Influenza infections, was used in 38.5% of cases (59% of SARS patients). A Spanish multi-center study that assessed patients with severe illness, antibiotic therapy was also widely used (GARCIA-SALIDO et al 2020). Patients in the MIS-C group were more frequently treated with corticosteroids, immunoglobulins and vasoactive drugs (100%, 100% and 84.6%, respectively). Due to a higher likelihood of thromboembolism, this group also received a higher percentage of anticoagulant therapy (76.9%). As the goal of MIS-C treatment is to reduce systemic inflammation and restore organ function, the treatment strategy proposed by consensus in Europe suggests immunomodulatory treatment for inflammation, support measures and management of post-coagulation stage (ESPOSITO et al, 2021). The consensus in America suggests the start of antithrombotic prophylaxis in children hospitalized with severe illness who have at least one risk factor for thrombosis or higher blood D-dimer levels (GOLDENBERG et al, 2020). In the present study, D-dimer levels were higher for all patients tested. In regard to outcomes, the prognosis of patients included in our study was favorable. The average time spent in ICU was 4 days, and the average admission time was 12 days, being shorter in MIS-C patients (8 days), despite the severity of these cases, which is in accordance with many studies (GARCIA-SALIDO et al, 2020); TOBA et al, 2021; PRATA-BARBOSA et al, 2020). There was one fatal case: a male patient, younger than 1 year old, who presented with SARS and was previously healthy, corresponding to 2.6% of the critical case sample. A meta-analysis conducted recently by Toba et al (2021), as well as a Brazilian study by Oliveira et al (2021) and an African study by Nachega et al (2022), showed similar mortality rates. Studies assessing which factors could predict severe pediatric COVID-19 infection showed that a younger age, pre-existing severe chronic comorbidities, male sex, as well as signs and symptoms of lower respiratory tract infection in presentation could be considered risk factors (GARAZZINO et al, 2021).

Conclusion: In the present study, among patients admitted to ICU, SARS and MIS-C were the most frequent presentations. More than half of the patients were previously healthy, especially among those with MIS-C. Treatment included clinical and ventilatory support and outcomes were satisfactory in all cases, except that of one infant, which progressed to death. Multi-center studies are necessary to provide further clarification on severe illness in pediatric patients infected with SARS-CoV-2, as well as to determine possible risk factors leading to severe or fatal disease progression.

Keywords: SARS-CoV-2. COVID-19. Pediatrics. Pediatric intensive care.

Evaluation of lymphocytes on children and teenagers after chemotherapy treatment for Acute Lymphoblastic Leukemia

Gabriel Borges Copeland[1]
Robéria Mendonça de Pontes[1]
Anna Carolina Silva Dias[1]
Ricardo Camargo[1]
Karina Mescouto de Melo[1]
Cláudia França Cavalcante Valente[1]

Abstract

Introduction: Acute Lymphoblastic Leukemia (ALL) is the most common kind of cancer in childhood, and the last decades witnessed an evolution of the biological knowledge of the disease and its treatments. Considered a fatal disease, ALL nowadays has a 90% chance of cure in the best centers. The medications used to treat ALL lead to immunosuppression, which promotes the occurrence of infectious complications. In this study we will evaluate the recuperation of the immune system after the chemotherapy treatment for Acute Lymphoid Leukemia.

Objective: Evaluate the evolution of the lymphocytes on children and teenagers that were treated with chemotherapy for Acute Lymphoblastic Leukemia (ALL) in the Hospital da Criança de Brasília (HCB) between March 2021 and January 2023.

Methods: Descriptive, prospective and longitudinal study, carried out between March 2021 and January 2023, using the peripheral blood of children and teenagers at 1, 3 and 6 months after the end of chemotherapy treatment for ALL. The samples were analyzed by flow cytometry to quantify the number of total lymphocytes and their respective subpopulations, as well as natural killer cells (NK). Redcap and Excell files were used to store all the data collected. The statistical analysis was done on software IBM SPSS (Statistical Package of Social Science)23, 2015.

Results: Eight (8) patients were included, with ages between 3 and 14 years, six (6) males and two (2) females. The majority of the patients were girls (75%). B Lymphocytes cells (CD19+) showed significant increase (p=0/008) between the periods of one (1) and six (6) months after chemotherapy. Naïve B cells and class switched memory cells showed an increase of 111,8 cell/mm³ to 557,6 cell/mm³ (p=0,008) and 7,0 cell/mm³ to 21,3 cell/mm³ (p=0,018) on their respectively medians, between the periods of one (1) month and six (6) months. Non-class switched B lymphocytes had a change of 3,9 cell/mm³ to 16,6 cell/mm³ (p=0,037) in its medians between the periods of one (1) and three (3) months. T lymphocyte cells populations did not show a significant increase in their cell numbers in the three periods that were studied.

Conclusion: In our population, B Lymphocytes (total, naive and switched memory) showed a faster recovery to the treatment of acute lymphoblastic leukemia, than the T lymphocyte subpopulations. B lymphocytes in the immune system represent the cells responsible for the production of antibodies and memory cells, and they have an important function for the recuperation of the immune system of the patient, enabling better response to infections and immunization, which, in turn, can guarantee better quality of life to the children and teenagers that have undergone successful treatment against the cancer. Furthermore, the vaccination calendar can be safely and effectively continued**.**

Keywords: Immune reconstitution. Children. Lymphoblastic Leukemia. Chemotherapy.

1. Hospital da Criança de Brasília José de Alencar (HCB)

Evaluation of pain control in children admitted to the palliative care service of a tertiary pediatric hospital

Maria Clara Feitosa da Silva[1]
José Carlos Martins Córdoba[2]

Abstract

Introduction: Pediatric palliative care is the approach that provides total care of body, mind and spirit for children suffering from chronic, progressive, refractory, debilitating, or life-threatening diseases. It is targeted in integral and continuous care, improving the quality of life and relieving the suffering of the patients and their families. One of its main pillars is pain management. The assessment and description of the symptom pain, as well as the response to treatment should be performed whenever possible to ensure the dignity and autonomy of the patients.

Objective: To describe the clinical characteristics of pediatric patients admitted to pediatric palliative oncology care service from August 2021 to February 2023, in order to evaluate pain prevalence at admission in the palliative care and in their last week of life; describe how the symptom was evaluated and the response to treatment, in order to understand the effectiveness of pain control in patients participating in the study.

Method: This is a quantitative, observational, cross-sectional research with data analysis from electronic medical records of 62 patients admitted to the palliative care service between January 2017 and December 2021, who presented the symptom of pain at admission, or in the last week of life. Data collected included epidemiological data, presence, and description of the pain, as well as the type of treatment, and response to treatment.

Results: Among the 62 patients analyzed, only 5 (8,1%) are not deceased. The median age at death of the patients was 10 years, and the Median time between admission in palliative care and death was 104 days. The most prevalent diagnosis was CNS tumors in 50% of the patients, followed by hematological diseases in 22.6%. Pain was the most prevalent symptom in the group, followed by neurologic deficits, and nausea / vomiting. The most frequently used scales for symptom assessment were the pain ruler and the visual pain scale. More than half of the patients had pain with lack of control on admission, and most took Dipyrone in these cases. The medication most often prescribed for moderate and severe pain was Morphine, followed by adjuvant medications such as Amitriptyline and Gabapentin. All deceased patients required analgesia in their last week of life, but it was effective in only 54.9% of the cases. The most frequently used medication was continuous doses of Morphine. 35.7% of these patients required analgesic sedation.

Conclusion: Optimizing the description of symptoms and the therapy used to control pain in pediatric palliative care is a challenging task. Pain is a prevalent source of suffering, and a challenging symptom to control among pediatric oncology patients. The multidisciplinary team plays an important role in this process, recognizing the unique needs of these patients and their families, and providing symptom relief through pharmacological and non-pharmacological measures. There is room for improvement in the service, especially regarding the adequate description of the symptom, as well as the response to the type of treatment offered. The creation of a managed pain control protocol for better assistance of these suffering patients is proposed.

Keywords: Palliative Care. Integrative oncology. Cancer pain. Patient care team.

1. Universidade Católica de Brasília

2. Hospital da Criança de Brasília José de Alencar (HCB)

Experience report on the implementation process of Hospital Epidemiological Surveillance in a specialized hospital in the Federal District

Larissa Cristina Araújo Barrozo[1]

Abstract

Introduction: The Epidemiological Surveillance (ES), established by Law No. 6.259 of October 30, 1975, is one of the main components of health surveillance. The Epidemiological Surveillance of Hospitals was established in Brazil as a way of strengthening and decentralizing the ES, and considering that the hospital environment provides essential and timely strategic data for the knowledge of the profile of illness of the population, The *Hospital da Criança de Brasilia* plays an important role in the epidemiology of the country, since it is a hospital with 202 inpatient beds, specialized in various pathologies that serves the child population of the Federal District and other states.

Objective: To report on the implementation of a hospital Epidemiological Surveillance model in a specialized hospital in the Federal District.

Method: This is an experience report. To do so, a specific nurse was hired to perform the functions and computerized tools were used to make the compulsory notifications of diseases, as well as work instructions for the teams to consult. Among the computerized tools are the transmission of the request for medical examination linked to the filling of the compulsory notification, to which the examination is related, and the filling of the notifications directly in the patient's electronic medical record. All compulsory notifications and laboratory tests that may be related to the compulsory notification aggravations generate real-time data in the hospital epidemiological surveillance dashboard, contributing to the institution of a model of active and retroactive search, based on technological resources, reducing the time spent by professionals who need to fill out specific forms and assist the Hospital Epidemiological Surveillance in identifying the aggravations within the institution.

Results: After the implementation, a significant number of notifications made in the hospital was noticed, and better response to the demands passed by the Ministry of Health and specific bodies of the Epidemiological Surveillance of the Federal District. From August (start of implementation) to December 2022, 302 mandatory notifications were made in the hospital.

Conclusion: It was possible to conclude that the adoption of computerized measures and partnership with the teams contribute to the process of notification of epidemiologically important diseases. However, it is frequent that there is underreporting of diseases in health institutions, so it is essential that health education, for completion of compulsory notifications, is perennial in order to portray as accurately as possible the profile of the institution.

Keywords: Public health surveillance. Epidemiological monitoring. Epidemiologic surveillance services. Disease Notification.

1. Hospital da Criança de Brasília José de Alencar (HCB)

Exploring large deletions of GATA1 and their implications for molecular diagnosis of myeloid leukemia of Down syndrome

Agenor de Castro Moreira Santos Júnior[1]
Ricardo Camargo[1]
Brenno Vinícius Martins Henrique
Marina da Costa Ribeiro[1]
Bruna Candido Guido[1]
Isis Maria Quezado Magalhães[1]

Abstract

Introduction: Trisomy of chromosome 21 combined with mutations in exons 2 or 3 of the GATA1 gene are important factors in the development of Myeloid Leukemia of Down Syndrome (ML-DS). Pathogenic mutations render the long isoform of GATA1 expression non-viable in blasts. The mutations in GATA1 are diverse, ranging from substitutions to large deletions. Due to the low allelic frequency of the mutation, which is associated with a disease that usually progresses with a low number of blasts, diagnosing this alteration molecularly is difficult. Current sequencing strategies, whether in genetic or exome panels based on amplicons or exon 2 sequencing by Sanger, generally use probes that flank regions that may be deleted in patients. This results in sequencing only wild-type copies, which cannot detect the mutation.

Objective: To develop an alternative strategy for investigating patients with typical clinical presentation of ML-DS without detectable mutations in the first sequencing of the GATA1 gene, and to describe large mutations that render the expression of its long isoform non-viable.

Methodology: An alternative method was developed based on two new strategies. Gene expression analysis of the short and long isoforms of GATA1, as well as an increase in the sequenced region, including part of the intron 1, together with exon 2 by the Sanger technique.

Results: Two cases that previously did not have mutations detected but had clinical and immunophenotypic tests that characterized ML-DS, were reevaluated with the proposed new strategy. In both cases, large mutations that made the short isoform of GATA1 expression non-viable were found. In both cases, the complementary region to the forward primer of the classic strategy was deleted, resulting in the amplification of only the wild-type sequence.

Conclusion: In summary, the research shows that current sequencing strategies used for detecting GATA1 mutations may miss large deletions, making the diagnosis of ML-DS difficult. The use of amplicon strategies, if designed in gene regions juxtaposed to the exons of interest, can mask the result by not detecting large mutations in somatic alterations or even in germline alterations in heterozygosity. To overcome this challenge, the study developed an alternative approach based on gene expression analysis and an expanded sequencing region, leading to the identification of mutations that were previously missed. The findings highlight the importance of customizing sequencing strategies for each case to improve the accuracy of molecular diagnosis in precision medicine.

Keywords: Myeloid leukemia. Down syndrome. GATA1.

1. Hospital da Criança de Brasília José Alencar (HCB)

Family-centered care approach in the rehabilitation of children with cerebral palsy: experience report

Thamiris da Silva dos Santos[1]
Sthefany da Silva Souza
Ana Priscila da Silva Teixeira
Nayara Cristina de Jesus Silva
Rafaela França de Sousa
Kênnea Martins Ayupe
Aline Martins de Toledo

Abstract

Introduction: Family-Centered Care (FCC) is a prominent approach in early intervention and pediatric rehabilitation, including for children with Cerebral Palsy (CP), characterized by the humanization and inclusion of the family in the care process, particularly in ministering psychosocial issues and seeking family involvement. For this, it is considered that each family is unique, constant in the child's life and a specialist in the child's abilities and needs. Therefore, the family works together with health professionals to make informed decisions about the services and support that the child and family receive.

Objective: To present the experience of the extension project Cuidar de PC (Care for CP), affiliated to the Universidade de Brasília – Distrito Federal, which works with family-centered care for children with cerebral palsy.

Methods: Descriptive study, based on data and practical experiences of the Cuidar de PC Program, carried out at the University Hospital of Brasília (HUB). Children with CP receive multidisciplinary care from doctors, occupational therapists, speech therapists and physical therapists, based on the CCF method, in addition to including physical therapy assessment of structure, function, activity and participation, based on the SMART method (Specific, Measurable, Achievable, Relevant, Timed). Guidelines for the family, always considering their perspectives and goals are also provided. Based on the full assessment, level of gross motor function, and clinical type of CP, the children are then referred to the appropriate services relevant to their current status.

Results: In Cuidar de PC, the therapeutic approach considers the family's perspective and expectations, not limiting the treatment solely to the professional's perceptions. In addition, the service is not restricted to the professional's area of activity, and the necessary referrals are made, allowing the child with CP and their family to be integrated into a care network that meets all individual needs. Thus, effective and welcoming support is provided for the family, as well as an indication of resources that are compatible with their current socioeconomic situation. Therefore, during the follow-up, the family actively works in the elaboration of the treatment to be applied, establishing common goals which are followed by daily management guidelines, such as adequate positioning of the child in the home environment, adequate ways of providing stimulations that favor the child's development in everyday life, information on care and actions necessary for the child's evolution. With this, it is possible to qualify the family to play an active and efficient role in the process of care and development of the child with CP, in physical as well as psychological and social aspects.

Conclusion: Based on the clinical experience of care provided by 'Cuidar de PC, a considerable contribution can be seen from the CCF approach applied to the therapeutic evolution of the children assisted, as they receive the resources and essential multidisciplinary referrals so that all their needs and individual demands are met. A therapeutic plan is developed together with the family, ensuring their active insertion throughout the treatment.

Keywords: Cerebral palsy. Family-centered care. Children with disabilities.

1. Universidade de Brasília (UnB)

Feelings of caregivers of children with complex health conditions in a transition unit to home care

Rebecca Camurça Torquato
Eilen Tainá Matos Ferreira
Angelo Ramos Junior
Luana Nunes Caldini
Cristiana Brasil de Almeida Rebouças

Abstract

Introduction: The routine of caring for children with complex health conditions requires a rearrangement and management by the family in order to be able to offer appropriate care to these patients. Part of this is carried out in a hospital environment, in which families are offered the scientific and assistance support necessary for their training in the care of their children. However, in the meantime, doubts may arise about how the long-awaited home care should be.

Objective: To describe the feelings experienced by caregivers of children with complex health conditions when faced with the transition from the hospital unit to home care.

Method: A descriptive study with qualitative approach, carried out with eight caregivers of children with complex health conditions in a transition from the hospital unit to home care at a children's hospital in the State of Ceará, Brazil. Data collection was carried out between September and November 2019 through semi-structured interviews. Data were analyzed using the content analysis method. Research was approved by the Research Ethics Committee of the aforementioned institution, with CAAE nº: 17608819.1.0000.5042.

Results: Eight caregivers were interviewed at the hospital transition unit, most of whom were mothers of these children. Most of the children hospitalized in the unit used invasive ventilatory support and gastrostomy for food and medication. Caregivers received training at the unit related to airway aspiration procedures, administration of diet and medication, as well as performing bed baths and skin care, performing dressings and intermittent bladder catheterization. Regarding the experiences of the participants in the unit, the presence of divergent feelings was observed in relation to the idealized home care. The satisfaction of taking the child home and the hope of being with the family again were emotions seen as positive during this process and that pushed these caregivers to face the difficulties so as to reach the dreamed goal. As negative sensations, there was a frequent report about the fear of taking the child home, both related to the concern of missing something for the child at home, as well as the fear of the child getting sick or having some health complication at home. Anxiety was also a feeling present in the speech of these mothers, both the anxiety to return to the family environment, and the anxiety of not knowing what awaits them in this new phase of childcare.

Conclusion: It was noticed that not only does the child suffer from complex illnesses, but the family is also impacted by the relational, environmental and emotional changes they face when experiencing the role of caregivers. During the parents' training process and transition to home care, it is essential that the health team, and especially the nurse, be aware of the feelings experienced by the family, with the aim of offering support and providing tools and strategies that may facilitate this process. In addition, it is important to preserve the mental health of the caregiver, so that he or she provides adequate care for the child.

Keywords: Caregivers. Emotions. Home Care Services. Child. Chronic Disease.

First impressions of an NGS-based gene panel for comprehensive analysis of genetic alterations in pediatric leukemia

Ricardo Camargo[1]
Agenor de Castro Moreira dos Santos Júnior[1]
Bruna Cândido Guido[1]
Marina da Costa Ribeiro[1]
Larissa Lemos Mendanha Cavalcante[1]
João Lucas Cruz Souza[1]
Isis Maria Quezado Magalhães[1]

Abstract

Introduction: Acute Leukemia (AL) is the most common neoplasm in childhood, representing 25% of all pediatric cancers worldwide. Although the number of new cases of leukemia has increased, the mortality of children with the disease has shown significant decline. This is due to the recognition of new actionable genetic-molecular markers and the development of new diagnostic and disease monitoring methods. Precise diagnosis at molecular level remains challenging due to the genetic and phenotypic heterogeneity of ALs. Conventional methodologies (generally the most accessible) do not have the necessary coverage and sensitivity to simultaneously cover multiple gene targets and therefore require a laborious testing flow. Thus, the implementation of a broader testing flow, such as a Next Generation Sequencing (NGS) panel, is of utmost importance for ALs.

Objective: To develop and validate a gene panel for researching genetic alterations in pediatric acute leukemias (AML, B-ALL, and T-ALL) through NGS.

Methods: The genes selected for the panel were curated from scientific articles, WHO and other institutions' manuals (e.g., LeukemiaNet, NCCN). 600 genes were selected, and the library preparation was performed by hybrid capture from total RNA extracted from 48 bone marrow aspirate or peripheral blood samples. Sequencing was performed on the NextSeq500 equipment (Illumina). Variant identification analyses were performed in the Cancer Variant Caller application (Illumina), gene fusion research, and gene expression analyses were performed in the DRAGEN RNA (Edico Genome) and TOPHAT (Illumina) applications, respectively.

Results: So far, 48 patient samples with AL have been tested. Of the 48 samples, 35 were ALL-B at diagnosis, one was ALL-T, four were ALL-B relapse, and eight were AML. Twenty samples had gene rearrangements previously identified by RT-PCR, such as BCR-ABL1, ETV6-RUNX1, PML-RARA, TCF3-PBX1. Among the samples with known rearrangements, only one did not have its fusion detected: AML sample with PML-RARA fusion. Of the samples that did not have previously identified fusions, six had gene rearrangements detected through NGS: ZMIZ1-ABL1, BRD9-NUTM1, RAF-TMEM40, RUNX1-CTC1. For SNVs and indels, some samples that had previously identified variants did not present detection through NGS. For example, deletions in IKZF1 and deletions and duplications in PAX5. For deletions, the absence of transcription or instability of the mutated transcript may be the cause of non-detection, given that it is an RNA panel. However, the possibility of non-detection due to the limitations of the algorithms used for variant calling cannot be ruled out. Therefore, some controls still need to be performed to validate the analysis pipelines.

Conclusion: Due to the heterogeneity of ALs, a genetic panel evaluated by NGS is of absolute importance. However, there are still difficulties in parameterizing pipelines for fusion research and variant identification from RNA. In addition, using RNA as template has its advantages, such as detecting fusions and analyzing gene expression, but also has limitations, the most important being information loss due to the absence of transcription or instability of RNA of some targets, dependence on gene expression for mutation detection, inability to analyze CNVs, and loss of precision in allele frequency.

Keywords: NGS. Leukemia. Biomarker.

1. Hospital da Criança de Brasília José Alencar

Fluid management in pediatric patients on invasive mechanical ventilation

Dofilia Nikomo Nunda Gil Chindombe[1]
Frederico Ribeiro Pires[1]

Abstract

Introduction: Patients subjected to mechanically invasive ventilation (IMV) are prone to increase in renin, which leads to stimulation of the renin-angiotensin-aldosterone as well as increased antidiuretic hormone secretion and atrial natriuretic peptide. These elements cause water and sodium retention, a reduction in urinary debt and subsequent hypervolemia, with consequently longer mechanical ventilation time, hospitalization at Intensive care Unit (ICU), and a need for diuretics and renal replacement therapy.

Objective: To evaluate the effect of hydration volume in the first 48 hours after admission and their consequences in patients subjected to invasive mechanical ventilation.

Method: Randomized survey was conducted, in patients admitted in the ICU of the Hospital da Criança de Brasília (HCB) aged between 1 month and 14 years, requiring IMV and that their diagnosis does not fulfill exclusion criteria, between: 08/01/2022 to 12/15/2022 (data collection period). The patients who were placed on IMV within the first 48 hours of admission in the ICU or in the previous 24 hours prior to admission were considered for the study, depending on the inclusion and exclusion criteria, and randomized in 2 groups (50% group and 80 % group). In the first 24h of IMV, they were venously hydrated according to the values predicted in the group they belong and had zero diet. After 24 hours, an enteral diet was introduced, still respecting the offer established in final water content, calculating it taking in consideration the venous hydration and diet. The information was harvested through a form and electronic patient file and included in the Redcap program.

Results: There were 43 patients in the study, of which 22 (51.2%) were randomized to the 80% group (G80) and 21 (48.8%) to the 50% group (G5O). The average age was 29 months (IQ 69), and the weight was 12.1kg (IQ 12.6). Lower respiratory tract was the most prevalent pathology with 28 cases (65.1%); average intubation time was 4.5 days (IQ 3.25); length of ICU stay was 11 days (IQ 8.5); the cumulative dose of furosemide in the first 48h was 1mg/kg (IQ 1.1); the accumulated HB in 48h it was 27.9ml/kg (IQ 72.4). The mortality was 3 cases (7.1%) on groups comparison, the G50 received 12.3 times more volumetric expansions between 24-48h (p 0.020) than the G80 also, G50 had 4.95 times more vasoactive drugs (VD) use than G80 (p 0.019). G80 patients had higher water offer, between 24 and 48 hours than the G50 patients (p 0.030). G50 patients had significantly greater creatinine values in 48h than the G80 (p 0.037), additionally they had higher urea, with a value of statistical significance close to (p 0,05).

Conclusion: Although the G50 received significantly more volume expansions and more VD, we cannot conclude that water restriction is harmful, as there was excessive use of diuretics, which can lead to hypovolemia and the need for more expansions, making it a vicious cycle. More studies in different centers are needed.

Keywords: Fluid therapy. Pediatrics. Respiration artificial.

1. Hospital da Criança de Brasília Jose Alencar

General oral manifestations resulting from chemotherapy in children with leukemia and its consequences

Marina Pimentel Freitas[1]
Ana Carolina Borges Penalva Ferreira
Julia Silva Vasques
Mirella Jackeline de Andrade Rezende
Luana de Oliveira Pires
Gabriela Ponte do Couto
Raquel Rodrigues Fonseca da Cunha

Abstract

Introduction: Leukemia is the most common cancer in pediatric age. The treatment is based on chemotherapy and the cure rate is around 90%. However, chemotherapy has adverse effects that affect oral health, such as destruction of oral mucosal tissue and infections. As a result, patients change their eating habits and oral hygiene.

Objective: The aim of this study is to evaluate the oral manifestations caused by the use of chemotherapy by children with leukemia and its consequences.

Methods: This study is a literature review in which 5 articles were selected from the databases "Scielo" and "PubMed", from 2018 to 2023 through the keywords 'chemotherapy', 'children', 'leukemia' and 'oral manifestations'.

Results: The results presented by the articles demonstrate the oral alterations in children related to leukemia and its treatment. Thus, it's possible to correlate the emergence of oral manifestations with the disease. The main oral alterations can affect the teeth, causing caries, the occurrence of dysbiosis of oral microbiota, affect the oral mucosal, generating petechiae, spontaneous bleeding and mucosal ulceration, which may contribute to opportunistic infections. Cammarata-Scalisi et al (2020) studies show that oral manifestations of leukemia in children are present in more than half of patients in the form of petechiae and spontaneous bleeding, in addition to mucosal ulceration. Also, when there is not good oral hygiene, the chances of infection and complication of the condition of patients undergoing treatment increases. Therefore, poor oral hygiene is a risk factor for the patient's prognosis. According to Wang et al (2021), the oral microbial composure of all groups of patients at chemotherapy treatment has significant modification of structure composition, which is related directly to oral complications. Besides, the therapy against cancer in pediatric patients may affect teeth development and certain complications of chemotherapy such as hemorrhage have been reported. The administration of some classes of chemotherapeutic agents commonly used for the treatment can result in disturbing the odontogenesis. Yet, the precise mechanisms that induce dental agenesis and aberrations through chemotherapy is still unclear. As a consequence of the oral alterations, children change their eating habits, tending to consume more high-energy foods and sugar-rich drinks, in small portions, trying to reduce xerostomia and avoid the nausea and vomiting caused by the chemotherapy. In this context, the study by Juarez-Lopez (2018) shows that children in advanced stages tolerate only liquid foods, requiring parenteral feeding.

Conclusion: Parents or guardians should be aware of the care and hygiene of the oral cavity of patients undergoing treatment. Thus, the dental and periodontal treatment should always be planned and involve a multidisciplinary team, including hematologists, pediatricians, oncologists, dentists, and dental surgeons.

Keywords: Oncologists. Leukemia. Oral manifestations. Pediatricians.

1. Universidade Católica de Brasília

Health education to high school students: a cardiopulmonary resuscitation and disengagement maneuvers workshop

Igor de Souza Gramacho[1]
Catarina Flor Silva de Araújo
Gustavo Vinícius Silva Brandão
Nathália Rafaela Maria da Costa
Letícia de Cássia Rodrigues de Oliveira
Solange Baraldi
Andréia Guedes Oliva Fernandes

Abstract

Introduction: Basic Life Support (BLS) consists of a series of maneuvers performed in victims of different incidents, such as cardiopulmonary arrest (CPA) and foreign body airway obstruction (FBAO). BLS is the primary way of avoiding death and possible complications (GONÇALVES *et al*., 2011), and for that reason, it is important that everyone has that awareness. Health education aims to bring knowledge to the population so they can have more autonomy over their own health and that of the ones closest to them (FALKENBERG *et al*, 2014).

Objetive: The goal of this report is to share the experience of a BLS health education workshop focused on CPA and FBAO, offered to students from public high schools in Brasília in 2022.

Methods: This document is an experience report regarding a university extension activity named Basic Life Support of CPA and FBAO conducted in August 2022 which targets public high school students in Brasília. Low fidelity clinical simulation in adults and newborn medical torso mannequins were used to train Cardiopulmonary resuscitation (CPR).

Results: This extension activity was developed by 'Continuous Action Extension Project' called 'Liga Acadêmica de Enfermagem em Trauma e Emergência (LAETE)' mentored by the main teacher. The training session had three steps: 1– Theoretical presentation of the subject 2– Visual demonstration of techniques 3– Invitation for the audience to practice BLS techniques for FBAO and CPR on average torso mannequins (low fidelity clinical simulation) in order to better retain the information in a ludic way. The workshops were planned in order to provide moments of active participation through interactions between project members and the audience, with questions and practice held at the end of the theoretical exposition. Adapting the technical-scientific vocabulary to a younger audience and the use of visual resources are important for better understanding. With the use of low-fidelity realistic simulation, it was noted that the audience had the opportunity to learn the course of action and the relationship between theory and practice. It was perceived that the students had a tough time memorizing Brazil's emergency numbers. Therefore, health education classes in emergency and urgency situations need to be expanded, since the first out-of-hospital chain of survival step is the early identification and activation of emergency response.

Conclusion: For lay people, health education actions on first aid maneuvers for CPA and FBAO using low-fidelity realistic simulation, is a strong health promotion strategy. This increases survival rate and reduces the risk of complications due to the possibility of action by anyone on the scene who has the knowledge about these maneuvers.

Keywords: Health education. Cardiopulmonary resuscitation. Gagging adolescents. Simulation training.

1. Universidade de Brasília (UnB)

Hypogammaglobulinemia in a patient with UDP-galactose-4-epimerase (GALE) deficiency galactosemia: a case report

Laryssa Kellye Pereira Soares Sousa[1]
Ricardo Camargo[2]
Agenor de Castro Moreira dos Santos Júnior[2]
Robéria Mendonça de Pontes[2]
Cláudia França Cavalcante Valente[2]
Fabíola Scancetti Tavares[2]
Karina Mescouto de Melo[2]

Abstract

Introduction: Galactosemia is an inborn error of galactose metabolism, caused by an impairment of any one of the three galactose metabolizing enzymes: galactose-1– phosphate uridylyl transferase (GALT), galactokinase (GALK) and UDP-galactose 4-epimerase (GALE). GALE is the rarest condition among the three types and can be undiagnosed because of its rareness. The most common clinical features are hypotonia, poor feeding, vomiting and weight loss. Moreover, some long-term characteristics are developmental delay, sensorial hearing loss and short stature. Immunodeficiency is not usually described.

Objective: To report a rare case of GALE deficiency in a patient referred to immunologic evaluation due to low Immunoglobulin (IgM and IgG) levels.

Methodology: Clinical and laboratory data collected from medical records.

Results: A six-year-old girl, born from non-consanguineous parents, who presented a clinical feature of fetal distress and, during the neonatal period, had diagnosis of neonatal sepsis, periventricular hemorrhage IV, interatrial communication and anemia. In her first month of life, the patient spent 12 days at the Intensive Care Unit, 5 days under mechanical ventilation. Due to an abnormal newborn screening result, Galactosemia was suspected, but later this diagnosis was excluded since the patient had normal dosage of GALT in the blood sample. At 4 months of age, the patient was referred to an immunology evaluation because of low IgG and IgM levels, anemia, neutropenia, and lymphopenia. Baseline standard immunological tests showed hemoglobin of 10,0 g/dL, lymphocytes of 2142/mm³, neutrophils of 1218/mm³, platelets of 134.000/mm³, IgG of 236, and IgM of 18,7 (below 2 standard deviations from the mean values for the age). Low CD4, CD8 and CD19 counts, normal TREC and KREC counts (50 and 34, respectively) and slightly increased double negative T cells (3,3% of TCD3+ cells) were also reported. The patient started to receive regular Immunoglobulin Replacement Therapy (IgRT) at 5 months of age, the treatment is still in progress and currently she has normal IgG serum levels. At the age of 5 years, with a combination of heart disease, hypogammaglobulinemia, lymphopenia, neutropenia with undefined cause, a whole exome sequencing (WES) was performed and revealed two mutations in GALE gene: c.408C>A(pathogenic) and c451G>A (variant of uncertain significance). The patient is alive and has a speech delay. She is in multidisciplinary care, with a lactose-free and galactose-poor diet, under regular IgRT and waiting for heart surgery.

Conclusion: GALE mutation is a rare type of galactosemia, and the presence of abnormalities in the immune system is not commonly described. Here we report, as far as we know, the first Brazilian case of GALE deficiency manifested with antibody deficiency.

Keywords: Epimerase Deficiency Galactosemia. Galactosemia. Immunologic Deficiency Syndrome. Pediatrics. Antibody Deficiency Syndrome.

1. Universidade de Brasília (UnB)
2. Hospital da Criança de Brasília Jose Alencar (HCB)

Identification of the complex chronic condition in children by Pediatric complex chronic conditions classification system version 2: application in SIH-SUS

Patrícia Vicente Oliveira[1]
Luciana Bertoldi Nucci

Abstract

Background: The definitions by Feudtner, Christakis & Connell (2000) and their update Feudtner *et al.* (2014) have been the most widely employed to identify and classify children with complex chronic conditions in epidemiological studies.

Objective: Describe the experience of using the Pediatric complex chronic conditions classification system version 2 (Feudtner *et al.*, 2014) to identify children with complex chronic conditions in the Hospital Information System (Sistema de Informações Hospitalares –SIH) of the Unified Health System (Sistema Único de Saúde –SUS) in an epidemiological study.

Methods: Experience report of the application of the pediatric complex chronic conditions classification system version 2 in SIH-SUS, in a temporal analysis of an epidemiological study. The data sheets with the hospital admissions for the analyzed period (2009-2020) were extracted from SIH-SUS by means of the method proposed by Saldanha, Bastos, and Barcellos (2019), which consists of using an algorithm made available in a package developed for the R statistical program called microdatasus, that makes it possible to download and preprocess data from the information system of interest or from several information systems directly. In this way, this tool optimizes the work for the selection of microdata files with the Unified Health System Informatics Department. To select only the hospitalizations of children diagnosed with complex chronic condition, in addition to the age range variable, was used the R Package for Pediatric Complex Chronic Condition Classification developed by Feinstein *et al.* (2018) to generate the complex chronic condition categories proposed in the Pediatric complex chronic conditions classification system version 2.

Results: The strengths of the aforementioned method were the identification of a wide range of conditions that characterize pediatric CCC, considering that the Pediatric complex chronic conditions classification system version 2 presents diagnostic codes (ICD-10) from several categories (malignancy, cardiovascular, hematological/immunological, neuromuscular, metabolic, prematurity and conditions resulting from the neonatal period, gastrointestinal, renal/urological, other genetic/congenital defects, respiratory, transplants and technological dependence); the ease and effectiveness of application for large hospital record archives, in addition to the fact that R Package for Pediatric Complex Chronic Condition Classification is free of charge. The limitations were that for future studies, it will be necessary to update the classification system (no match for ICD-11), as it was not very effective in identifying technology dependence in the SIH-SUS In addition, the definition is limited to the diagnosis code, therefore, it does not consider all the social determinants of health involving CCC status. Other difficulties encountered in the method described involved the SIH-SUS itself: it was not possible to identify hospital readmission, possibility due to human error in the registration of the disease in the Hospital Admission Authorization (Autorização de Internação Hospitalar [AIH]) and the secondary diagnostic codes were poorly reported making it difficult to identify multiple complex chronic conditions.

Conclusions: Despite the limitations, the Pediatric complex chronic conditions classification system version 2 is still the most commonly used system to identify pediatric CCC in large samples, such as epidemiological studies. Improvements in this classification system, as well as in the source system (hospital records) are needed to identify pediatric CCC more accurately.

Keywords: Pediatrics. Hospital Information System. International Classification of Diseases.

1. Pontifícia Universidade Católica de Campinas (PUC-Campinas)

Impacts of antibiotic exposure on the neurological and immunological development of children

Ádria Maria Nascimento Junior[1]
Mario Augusto Rego de Macedo

Abstract

Introduction: The development of the neurological and immunological systems starts in the maternal womb as early as the third week of pregnancy and is heavily influenced by the gut microbiome. Numerous environmental factors encountered during this period can impact the composition of the gut microbiota and have long-term effects. Exposure to antibiotics, during this period has been linked to the development of multiple systemic diseases and metabolic disorders.

Objective and Methods: The purpose of this systematic review of the literature is to examine the relationship between antibiotic use and developmental impairments in children. To identify relevant articles, a comprehensive search was conducted in databases, including PubMed, Scielo, LILACS, Google Scholar. Inclusion criteria were applied to select articles published in Portuguese or English between 2017 and 2023 leading to 8 articles. The descriptors 'Gut Microbiome', 'Dysbiosis', 'Anti-Bacterial Agents', 'Fetal Growth', 'Child Development' were used.

Results: The gut microbiome plays a crucial role in the neurological and immunological development of children. Research has shown that the prenatal gut microbiome is particularly important for the development of motor skills. For instance, the presence of Fusobacteria has been associated with the development of high fine motor skills during the prenatal period, while it plays a significant role in the development of low fine motor skills in infants. The composition of the gut microbiome can be influenced by environmental, genetic, and metabolic factors that can dictate enterotyping, which is related to the prevalence of specific microbiome bacteria and affect future manifestations such as obesity and diabetes. Moreover, there is a bidirectional relationship between the brain and the gut microbiome, forming the brain-gut-microbiome axis that can be proven by the gastrointestinal manifestation provoked by stress and anxiety. The gut microbiome also plays a defensive role by competing with pathogens for nutrients, producing antimicrobial compounds and proteins, and stimulating the secretion of IgA. The trophic importance of the gut microbiome lies in its regulation of intestinal endothelium growth, the maintenance of endothelial integrity, and the regulation of immune system development and function. However, the use of antibiotics can disrupt the balance of the gut microbiome, resulting in reduced species diversity, altered metabolic activity, and the selection of antibiotic-resistant microorganisms. Antibiotic exposure during the perinatal period has been associated with the later onset of diseases such as asthma, obesity, inflammatory bowel disease. Similarly, antibiotic exposure in childhood has been linked to inflammatory diseases such as asthma, juvenile arthritis, type 1 diabetes, Crohn's disease, and mental illness.

Conclusion: Antibiotics, whether used by mothers at prenatal period or by infants in early life, can disrupt the balance of the developing microbiome, potentially leading to a range of adverse health outcomes. This includes impaired development of fine motor skills, increased risk of asthma, and impacts such as obesity and type 1 diabetes in adulthood. Therefore, it is crucial to carefully consider the use of antibiotics during these critical periods.

Keywords: Gut Microbiome. Dysbiosis. Anti-Bacterial Agents. Fetal Growth. Child Development.

1. CEUB

Impacts of implementing RT-PCR testing for SARS CoV2 in a specialized pediatric hospital

Fábio Conde Meireles Júnior[1]
Ivo Medeiros de Carvalho Amorim[1]
Marina da Costa Ribeiro[1]
Cristiane Feitosa Salviano[1]
Ricardo Camargo[1]

Abstract

Introduction: The SARS-CoV-2 pandemic arrived in Brazil in late February 2020 and the virus spread rapidly, over a short period of time. Several assistance and diagnostic demands arose such as testing patients for SARS-CoV-2 virus detection through the RT-PCR method, as the pandemic advanced the need for effective and rapid testing was essential. In the Federal District, where the Central Public Health Laboratory (LACEN) was responsible for testing in the public health network, the time to release the report was long and resulted in clinical and financial management impacts. The Hospital da Criança de Brasília José Alencar (HCB) is a public and pediatric hospital with 202 inpatient beds, 8 operating rooms, 38 beds in Intensive Care Unit (ICU). The HCB sought an effective way to optimize the testing and the delivery time of diagnosis.

Objective: To describe the impact of implementing RT-PCR tests for SARS-CoV-2 in bed management logistics, with an impact on the reduction of financial costs and on the agility to release isolation beds.

Method: This is an experience report with analysis of managerial database from the Translational Research Laboratory (LPT) and Statistics and Controllership Center (NEC). Descriptive statistics were performed with the frequency presented in tables and graphs using Excel software.

Results: The LPT was enabled and certified by the LACEN of the Federal District to perform testing for COVID-19 on April 30, 2020. The unit cost was R$48.57. The average cost charged by private laboratories in Brasilia was R$ 200.00 (Sabin Medicina Diagnóstica, Laboratório Exame, and Fleury Medicina e Saúde), an amount approximately 76% higher than the test performed at the HCB. The time to release the reports at the HCB is 4:30h. LACEN, on the other hand, took 24 hours or more to release the tests. The speed and efficiency contributed to the reduction of costs of inputs and medicines. The HCB also adopted the testing of employees and carers. In the period between May 18, 2020 and December 31, 2020, 620 tests were performed, of which 4,962 in employees (24.06%), 8,482 in patients (41.14%), and 7,176 in carers (34.80%). Of this total 1,884 were positive and 441 inconclusive. In 2020 we had 150 hospitalizations of patients diagnosed with SARS-COV-2, 163 patients hospitalized in 2021 and in 2022 the total number of hospitalized patients was 183.

Conclusion: The diagnostic tests for SARS-COV-2 at HCB allowed a fast, efficient, and low-cost diagnosis, contributing directly to the reduction in hospital occupancy rate, isolation beds, and economy of supplies and medication. This efficiency optimized hospital occupancy. The fact of extending testing in two distinct periods, releasing negative patients from isolation beds and keeping only positive patients, increased the number of vacant beds for suspected patients in an environment of specialized pediatric bed shortage.

Keywords: COVID-19. Management health economics. Infection. Contagion. Pediatrics.

1. Hospital da Criança de Brasília José Alencar (HCB)

Implementation of an inspection plan in contracts signed by a social health organization for the management of a pediatric public hospital

Joseete Mendonça Mesquita dos Anjos[1]
Helen Cristina Araújo Cardoso Silva[1]

Abstract

Introduction: The analysis of contractual compliance, from its planning to completion, involves the execution of operational, technical, and administrative activities by different sectors of an organization. In this context, in addition to establishing criteria for the continuous evaluation of the quality of the services provided, it is necessary to continuously construct and manage knowledge, in order to reduce sectoral information gaps and stimulate the effective sharing of information between sectors of the institution. The need for deconstruction of barriers, effective dissemination of information and exchange of knowledge about the management of the contractual life cycle between sectors resulted in the elaboration of the Inspection Plan, an instrument elaborated from the analysis of data and mapping of risks of acquisitions and services demanded by the technical unit of a pediatric public hospital in the Federal District.

Objective: To report the experience of the creation, validation and operationalization of the Contractual Supervision Plan, in order to facilitate interorganizational communication and define key indicators for the examination of the overall performance of each contract.

Method: Report and analysis of process tracking type experience through documental analysis and participant observation in the period from 2021 to 2022.

Results: Experience described in three moments: the first refers to a brief characterization of contracts signed by the social organization the second narrates the path taken by professionals during the planning and preparation of the Inspection Plan and the third describes the operationalization of the new instrument. Effective knowledge management can play a primary role in the: effective decision-making capacity building focused on competitive intellectual capital and workforce development.

Conclusion: The processes of construction and management of knowledge within the organizational context is a complex task, which asks for continuous innovation. The compilation of data via the Inspection Plan has expanded the intellectual capacity of the people who make the decisions on a daily basis, which together determine the success or failure of the acquisitions and contracts made for the hospital. The Inspection Plan can be used as a diagnostic tool for the management of tax and contract managers, assisting in the adaptation of new employees and occasional changes in the sector or activity. It is indispensable to engage the training of the employees involved, in order to achieve better results in the dynamics of the sectors and strengthening the management of the contractual life cycle**.**

Keyword: Public health. Organization and administration. Contracts.

1. Hospital da Criança de Brasília José Alencar (HCB)

Incidence of skin lesion in a neonatal intensive care unit in western Paraná

Carolina Tenfen[1]
Rosane Meire Munhak da Silva
Grasiely Masotti Scalabrin Barreto
Eliane Roldao dos Santos Nonose
Adriana Zilly

Abstract

Introduction: The skin performs various important functions, among these, the maintenance of body fluids, thermoregulation, barrier against harmful agents, mechanical protection and tactile sensations. A large number of premature newborns need to be hospitalized in intensive care units and go through various procedures to survive. These, in turn, can cause some types of skin injuries, and consequently, pain, suffering and longer hospitalization time.

Objective: To report the incidence of skin lesions among newborns hospitalized in intensive care.

Method: Quantitative study, carried out in a neonatal intensive care unit of the university hospital in western Paraná. Data collection took place between October 2022 and January 2023, by a resident included in the Multidisciplinary Residency Program in Neonatology. The scores assigned on the Newborn Skin Condition Scale (ECPRN) were used to consider whether or not there were changes in the skin, a task routinely performed in the unit by nurses. The ECPRN was developed and validated internationally, and in Brazil it was cross-culturally adapted and validated in 2012. The ECPRN evaluates the following skin aspects: dryness, erythema and rupture/injury with scores between 3 and 9 assigned. The lowest score for the three aspects is 3, that is, the skin is intact, while a score of 9 means the skin has extensive damage. Newborns with a score between 5 and 9 were included and an instrument was applied, with the following variables: gestational age, birth weight, diagnosis, device causing the injury. This study was approved by the Ethics Committee.

Results: In the four-month period of data collection, 92 newborns were admitted and 17.4% developed some type of skin lesion. Newborns, hospitalized for respiratory distress due to Hyaline Membrane Disease, were mostly premature (<37 gestational weeks), with an average of 32 weeks, birth weight of 1,710 kg, appearance of the first lesion at 21 days of life, with 13 days for complete healing. The most frequent lesions were due to dermatitis in the perianal region (43.8%) surgical wound in abdominal region (25%) and pressure injury in occipital region (25%).

Conclusion: The results showed that the application of the ECPRN was an important tool to support nursing care in the neonatal environment. Promoting actions at the right time to prevent and treat skin lesions through ECPRN can enhance the good evolution of hospitalized newborns. The assessment of the newborn's skin is one of the indicators of quality of care and safety during hospitalization.

Keywords: Newborn. Skin. Neonatology. Nursing.

1. Hospital Universitário do Oeste do Paraná (HUOP)

Informatization of the contracting processes in a social organization administering a public, pediatric and tertiary hospital in the Federal District

Renato da Silva[1]
Amanda de Andrade Ferreira[1]
Deise Castro Oliveira[1]
Jorge Luiz Dias de Oliveira Junior[1]
Leandro Pereira Bias Machado[1]

Abstract

Introduction: A public management challenge is to fulfill the regulatory requirements with the maintenance of process efficiency. In the Federal District, Decree no. 33.390, of December 06th, 2011, discusses the contractual laws by the social organizations using public resources. The Decree stipulates a processual time for the execution of its phases, with the need for formalization and evidence of all its steps. The manual execution of the process can affect efficiency in the use of resources in the hospital environment, compromise the user service in case of delays in procedural time, hence the relevance of considering the possibility of computerization.

Objective: Evaluate the effect on the average purchasing completion time due to the computerization of the process.

Method: This is a descriptive survey of data on process completion time, bringing a historical series from 2019 to 2022 in a public and high complexity pediatric hospital in the midwest, managed by a social organization. During this period, the sector underwent computerization, moving from manual process management to using computerized platforms. The monthly results data were collected using the process tracking spreadsheet, identifying the historical records of process changes. It is a descriptive survey.

Results and Discussion: In the analyzed period, the following annual average time for process conclusion were: 2019 – 68 days, 2020 – 60 days, 2021 – 44 days, and 2022 – 36 days. When evaluating the success in reducing deadlines, we had to consider that in July 2020 occurred the migration from physical to digital processes, using the Electronic Information System – SEI®. In January 2021, the sector implemented an automated tool for quotations, computerizing the steps of the Purchasing Sector. Considering the specificities of the contracting process of the social organization, in the regulatory scenario of the Federal District, there is no system on the market that meets 100% of those needs. So, in 2021 and 2022, customizations were made, which allowed for the improvement the process, leading to a percentage reduction of 47% in the average time of the process, bringing agility to the process and ensuring the maintenance of the principles of legality, impersonality, morality, economy, and publicity.

Conclusion: In the period, there was a reduction of 47% in the average time to conclude the processes. This achieved reduction demonstrates how technology can contribute to improve a process, providing efficiency and security. The reduction in process time generates a positive impact on the entire supply chain, reducing the replenishment time and safety stocks and allowing improved response time to internal and external users.

Keywords: Purchasing. Hospital. Social organization. Process assessment. Unified health system.

1. Hospital da Criança de Brasília José Alencar (HCB)

Investigation of the scientific literature about palliative care in pediatric oncology in Brazil in the last 10 years

Pâmella Carneiro da Cruz
Mirielly Czarnobay Dezen
Rodrigo Rogério Vasquez Minõ Ugeda
Jamile Rodrigues Cosme de Holanda

Abstract

Introduction: The palliative philosophy began in ancient times with the first concepts about caring. Currently, the pediatric palliative care is considered the gold standard approach in child oncology. It is a comprehensive and multidisciplinary type of care for the child and the family which must begin from the moment of diagnosis. The logic of caring should permeate the relationships between the healthcare team and the patient and between the team itself. However, in Brazil, the subject aroused interest only 16 years ago. Therefore, there is a meaningful deficit in the academic education and in professional services of specialized institutions.

Objective: To investigate the scientific production on pediatric palliative care in oncology referring to Brazil in the last 10 years.

Methods: An integrative review of the literature was carried out. The keywords 'Palliative Care', 'Children', 'Oncology' and 'Brazil' were searched in Portuguese language in the Virtual Library of Health (BVS), Latin American and Caribbean Center on Health Sciences Information (LILACS) and in the Scientific Electronic Library Online (SciELO). Also, the keywords were searched in English in the Public/Publisher MEDLINE (PubMed). We included publications from 2013 to 2023 in English and Portuguese about Brazilian reality.

Results: Altogether, 55 publications were found. A reading was performed, and inclusion and exclusion criteria was used. 8 studies were selected for investigation of scientific production. The publications concerned humanization and the logic of caring by the multidisciplinary group. Generally, the studies conducted by doctors focused on early detection, survival, radiotherapy, pharmacologic and non-pharmacologic control of the symptoms, as well as the do-not-resuscitate-like order. In counterpoint, papers published by nurses and psychologists which addressed the education in pediatric palliative care, the care itself, the communication of bad news, the complementary and alternative therapies, the experience with the illness and death, the control of the symptoms and the usage of evaluation instruments were found. We noticed that the literature about the doctor-patient relationship and doctor-team relationship is still less explored in the context of pediatric palliative care in oncology.

Conclusion: The assistance with palliative care from the diagnosis of childhood cancer is fundamental for high quality treatment. For being considered the best type of approach for children with cancer, there is a need for further studies written by doctors about palliative philosophy, beyond palliative treatment, seeking the humanization of the relationships.

Keywords: Palliative care. Children. Oncology. Brazil.

Is there anemia in childhood kidney cancer survivors?

Ciro Moisés Oliveira Vieira dos Santos[1]
Ana Clara Pellizzaro da Motta
Estefânia Rodrigues Biojone[2]

Abstract

Introduction: Cancer and cancer treatment affect the quality of life of survivors in the short or long term, both physically and psychosocially. In this context, it becomes relevant to assess the child's nutritional status and health conditions, including iron kinetics, directly related to the quality of the pediatric patient's diet. (SILVA, K, et al., 2016).

Objectives: To assess the occurrence and incidence of iron deficiency anemia and iron deficiency in patients that received treatment for renal neoplasia during childhood.

Methodology: Retrospective study with patients aged between 1 month and 17 years, 11 months who had a diagnosis of renal tumor and were treated at the Hospital da Criança de Brasília from November 2016 to January 2022 and who had completed the treatment more than 6 months ago. As a screening, we evaluated the dosages of hemoglobin, mean corpuscular volume, mean corpuscular hemoglobin, serum iron and ferritin collected during follow-up after the end of cancer treatment. For the analysis, the last exam collected by each patient was considered. The reference values used to define anemia were Hb< 11.5mg/dL. Reference values for VCM and HCM were 77 to 95fL and 27 to 33 pg, respectively. Serum iron levels above 40Mol/L were considered normal.

Results: A total of 37 patients were included in the study, with a mean age of 81 months (median 75 months), 19 females and 18 males. In eight children, Hb levels were less than 11.5. Among them, 3 children had renal tumor recurrence (2 Wilms and 1 congenital mesoblastic nephroma) within less than 6 months of treatment completion. In these cases, MCV and HCM values were within the normal range, configuring normocytic and normochromic anemia. Two children (5%), aged 7 and 6 years old, presented microcytic and hypochromic anemia, suggestive of iron deficiency. In one case, the ferritin dosage was low, but the requested serum iron and transferrin saturation measurements were not collected during follow-up (poor adherence). In the other case, no iron deficiency was documented (Iron 48, ferritin 82). Both patients have unfavorable socioeconomic conditions. Two patients had borderline Hb levels (11.4), but without evidence of microcytosis and hypochromia and with normal serum and ferritin levels. One patient had normocytic and normochromic anemia. This patient has a tracheostomy and is accompanied jointly by pneumology for pulmonary sequelae due to prolonged extubating time.

Conclusion: Despite monitoring and follow-up after cancer treatment, iron deficiency anemia, without association with malabsorption syndrome, is still diagnosed in a population of cancer survivors. Strategies to encourage adequate follow-up and standardization of exams to be collected during follow-up are important to promote better health conditions for these patients. A curious finding in the present study was the persistence of normocytic and normochromic anemia in 3 cases of early recurrence of the renal tumor, during the period in which they were off treatment.

Keywords: Wilms tumor. Medical oncology. Follow up. Cancer survival. Child health.

1. Centro Universitário de Brasília (CEUB)
2. Hospital da Criança de Brasília José Alencar (HCB)

Mental healthcare on pediatric oncology offered by a non-governmental organization

Anice Holanda Nunes Maia[1]
Patrick da Silva Camêlo
Sandra Emília Almeida Prazeres
Jackson Matos de Sousa
Juvemar Rodrigues dos Anjos Júnior

Abstract

Introduction: When cancer strikes in children and teenagers, due to its stigmas and grievances, it causes them, and their parents fears and weaknesses and brings obstacles to treatment. In Brazil, the third sector has strong protagonism in its confrontation and acts alongside public health services.

Goal: To present a project for mental healthcare carried out by Associação Peter Pan, a non-governmental organization from Ceará, which works toward raising healing rates and improving life quality of children and teenagers with cancer, and their families.

Method: It is an experience report, a method consisting of turning in scientific and professional interventions in academic fashion. Results from the last three years of Integrare Project are reported: 2020, 2021, and 2022, with information gathered through monthly reports and processed by Excel software.

Results: The first measure in this context was the implementation of a psychological assistance service to patients and patients' carers, together with the reference treatment center, which assisted 1,172 patients, in different stages of child development, from 0 to 3 years old (18%), from 4 to 8 years old (29%), from 9 to 12 years old (23%), and 13 years old or more (30%), showing the impact of the illness on specific neuro psychomotor and social aspects, and the need for specialized interventions to minimize behaviors acquired from cancer treatment. As for diagnosis, leukemia stands for 55% and other neoplasms 45%, pointing out that most patients have undergone a longer and more aggressive chemotherapy treatment, common to lymphohematopoietic neoplasms. Out of every 10 patients treated, 8 had called for treatment for their hospital carers as well, fact which attests for the repercussion of family illnesses. As for the stages of treatment, 39% of the patients had showed demands around relapsing and palliative care, 38% related to recent diagnosis, and 23% to issues concerning treatment and the healing process, highlighting the positive relationship between the most critical stages of cancer and psychological suffering. 533 attendances of occupational therapy focused on strengthening t patients' autonomy, and 420 integrative and complementary therapies which have mitigated physical and emotional exhaustion, above all for patients' carers.,. Subsequently, psychiatric assistance was integrated to other interventions, in order to assist children and teenagers with psychological disorders due to the cancer experience and provide guidelines to parents, adding up to 205 attendances, which led to success in most critical cases. Mental healthcare have also included clown therapy which, adding up to 382 visits, provided humanization, interaction, expression, and mobilization of coping resources, maximizing children's spontaneous playfulness. During the Covid-19 pandemic interventions remained but were somehow restricted and happened with the support of communication technology.

Conclusion: Mental healthcare provides attention to the biological, psychological, and social needs of those assisted, based upon integration among healthcare professionals, integrative therapists, and the humanization policy which has proved to be an essential and effective complement to child and youth cancer and relevant action of the third sector.

Keywords: Mental health. Neoplasms. Pediatrics.

1. Associação de Combate ao Câncer Infantojuvenil

1q21.1 Microduplication – timely stimulation – speech therapy and physiotherapy improving quality of life: case report

Juliana Cristina Gonçalves de Menezes[1]

Abstract

Introduction: 1q21.1 microduplication is a rare genetic disease in which a piece of one of the chromosomes is extra in the body cells, with variable clinical presentation. We identified 50 reported cases worldwide. They can cause developmental delay and serious health problems: seizures, heart disorders, learning problems, autism, facial dysmorphia, genital anomalies, and congenital anomalies. Prevalence is 1</1000 000. Early diagnosis enables efficient multidisciplinary follow-up and identification of family members at risk for genetic counseling.

Goal: To describe the clinical case of a child with microduplication in early stimulation, in the synchronous performance of speech therapy and physiotherapy centered on the family, with increased life expectancy and functional gains.

Method: Case report of a male, 1 year and 1 month old, diagnosed with 1q21.1 microduplication, born at 38 weeks, presenting facial and body dysmorphisms, brain malformations, epiblepharon canthus, convulsive crises.

Results: The patient started physiotherapy and speech therapy at seven months of age, presenting global hypotonia, lack of cervical and trunk control, precarious reach of the upper limbs in the midline, no hand-to-mouth connection, no lateralization, no rolling over, severe oropharyngeal dysphagia, risks of laryngeal penetration and tracheal aspiration, food refusal. Currently, after 6 months of intervention, 3 to 4 times a week, for 50 minutes, and periodic monthly follow-up with a neuropediatrician, he is able to introduce food of thick liquid texture with adapted utensils, safely and with pleasure, with effective and risk-free swallowing. Improved motor development, with cervical and trunk control, sitting with trunk support, manipulating objects in the midline, lateralization and complete rolling with motor assistance have been observed.

Conclusion: Timely intervention associated with family-centered care, from an interdisciplinary perspective, can provide scientific information to offer professionals and families a new perspective on survival, gains in motor development and participatory and safe eating in rare syndromes. The child shown here benefited from this approach.

Keywords: Abnormalities. Rare diseases. Rehabilitation. Speech therapy. Physiotherapy.

1. Desenvolva Espaço Terapêutico

Mixed Phenotype Acute Leukemia with BCR-ABL fusion in a three-way translocation: a case report

João Lucas Cruz Souza[1]
Fernanda Vaz[1]
Felipe Magalhães Furtado[1]
Raquel Toscano[1]
Anna Carolina Silva Dias[1]
Robéria Mendonça de Pontes[1]
Ricardo Camargo[1]

Abstract

Introduction: Mixed Phenotype Acute Leukemia (MPAL) is a rare subtype that represents 2 to 5% of all pediatric acute leukemias. It is a heterogeneous group of acute leukemia with complex phenotype and genetic bases, whose challenge lies in establishing well defined diagnostic criteria, for example the need for exclusion of other leukemia subtypes, as the Acute Myeloid Leukemia (AML) with the t (8;21) which expresses markers of B cells. The diagnosis of this entity relies on combination of immunophenotype by multiparametric flow cytometry (MFC), cytogenetics and molecular biology studies.

Objectives: The aim of this study was to clarify and report a case of MPAL with a three-way translocation.

Methods: Bone marrow immunophenotype by MFC molecular studies were accessed by RT-PCR and MLPA techniques; cytogenetics analyses were performed by G Banding technique, and clinical data were identified in medical records.

Results: May 2017, female patient 9 years old, attended clinic with abdominal pain for 1 month, leukocytosis and anemia. Hemogram showed: Hb 13,7 g/dL leukocyte 52,1x103/μL platelets 147x103/μL, LDH 825 U/L peripheral blood smear analyses showed 47% of blast cells. MFC in bone marrow identified 48,3% of lymphoid blast cells with expression of CD45, cCD79a, CD19, CD34, CD10, CD22, CD58, nuTdTdim and CD38, without any expression of myeloid markers, compatible with common B cell Acute Lymphoid Leukemia (B-ALL). Molecular biology studies detected BCR-ABL1(p190) fusion and double deletion in the IKZF1 gene. Cytogenetic study showed 46, XX, t (9 22) (q34 q11.2), add (17) (p13) [13]/46, XX [5]. Treatment was performed under BFM 95 protocol with use of Imatinib. A month later, patient presented Diabetes Mellitus secondary to corticosteroid therapy and intolerance to Imatinib, starting Dasatinib instead. Minimal Residual Disease (MRD) was negative in D15 and D33, and treatment finished in May 2019, with complete remission until 2021. In April 2021 the patient returned to hospital with hepatosplenomegaly and hematological alterations (Hb 12,2 g/dL, leucocyte 93,8x103/μL with 29% of blast cells, and platelets 87x103/μL). Myelogram evidenced 27,5% of blasts with moderate size, regular nucleus, heterogeneous chromatin and agranular and scarce cytoplasm, indicating relapsed leukemia. MFC identified 40,02% of blast cells with 3 population expressing CD19, CD45dim, CD66c and CD13dim: population a) 21,81% with CD10, CD19, CD33dim, CD34, CD38dim, CD79a, CD81dim, and HLA-DR b) 15,31% with CD33dim, CD34dim, CD38dim, and CD79a and c) 2,91% with CD33bright, CD34, CD36partial, CD38bright, cCD79apartial, CD81dim, CD117, CD123, HLA-DR and MPO. Immunophenotype study was compatible with MPAL Lymphoid B/ Myeloid. Fusion BCR-ABL1 was confirmed again but mutation research in tyrosine-kinases domain of ABL1 gene was negative. Cytogenetic showed 50% of cells with t (9 22) (q34 q11.2) and 10% with t (9 22 17) (q34 q11.2 p13). Patient followed treatment under R16 protocol for B-ALL relapse, with negative MRD post-induction, pre-Hematological Stem Cell Transplantation (HSCT) and 6 months after HSCT.

Conclusion: MPAL is an aggressive entity with difficult diagnosis and treatment. Immunophenotype by MFC is fundamental for its differential diagnosis and follow up. A complete cytogenetic-molecular approach is important for diagnoses and prognoses, as well as to allow the identification of defined genomic subtypes that may help in the application of specific target therapies.

Keywords: Mixed Phenotype. Acute Leukemia. Complex translocation. BCR-ABL1 fusion.

1. Hospital da Criança de Brasília José Alencar (HCB)

Mobile applications in the management of pediatric patients with sickle cell disease: a bibliographic review

Giovana Cristina dos Santos Freitas[1]
Letícia Rocha Moreira
Mariana Quirino de Oliveira

Abstract

Introduction: Sickle cell disease (SCD) is characterized by the formation of structurally abnormal hemoglobin and deformation of red blood cells. This disease is one of the most common severe monogenic disorders in the world. In most cases, its clinical manifestations begin early in childhood, with significant impact, including blood vessel occlusion, multiorgan complications, several pain events and impaired quality of life. Currently, mobile apps have become a useful tool to assist pediatric patients with chronic diseases and their caregivers. In the context of SCD, symptom management usually begins at home. Thus, it is essential to know the role of these applications for the management of pediatric patients with SCD.

Objective: To identify the role of mobile applications in the management of pediatric patients with SCD, in order to highlight existing knowledge and gaps in the literature.

Methods: We conducted a narrative and descriptive literature review, with data collected from the database PubMed. The search was carried out with the Health Sciences Descriptors (DeCS/MeSH) 'Mobile applications', 'Child' and 'Anemia, Sickle Cell' associated to the Boolean Operator 'AND', and 18 articles were found between 2015 and 2022. Inclusion criteria were: (1) original articles and/or bibliographic reviews, (2) emphasis on the role of mobile applications in the management of children and/or adolescents with SDC, and (3) in English or Portuguese. Exclusion criteria were: (1) articles focused on adult health, and (2) studies in progress, with no results yet. After careful reading of the abstracts and application of inclusion and exclusion criteria, 6 articles were selected for qualitative analysis.

Results: In this context, 3 articles evaluated specific mobile applications: IManage, for self-management of pain and mood-Intensive Training Program to promote SCD knowledge, medication adherence and patient-provider communication, and Voice Crisis Alert V2 to provide access to educational resources on SCD, tools for children and caregivers to track and monitor symptoms and communication between the child or caregiver and providers. These studies showed that mobile applications provide significant benefits to the management of pediatric patients with SCD. They demonstrated benefits related to self-management skills, managing pain and mood, medication adherence and disease knowledge. The feasibility of a mobile application, with high satisfaction reported by children and caregivers, was also demonstrated. Benefits in psychosocial outcomes, such as pain impact, depended on full engagement in using the app. On the other hand, 2 articles pointed out that, although mobile applications have potential in the management of pediatric patients with SCD, there is a need for more evidence about their use and cost-effectiveness and for development of new tools. 1 article highlighted the need for these tools to be developed taking into account not only pediatric patients' need for medication reminders, but also their beliefs, emotions and barriers associated with medication adherence.

Conclusion: The use of mobile applications in the management of children with SCD is feasible and can be beneficial, however, additional studies are needed to optimize the applications of this assistance, expand its uses, develop new tools, and evaluate its cost-effectiveness.

Keywords: Mobile applications. Child. Anemia, Sickle Cell. Self-Management.

1. Universidade de Brasília (UnB)

Molecular diagnosis of rare variant hemoglobin Taybe: description of clinical and hematological findings of a case in the Federal District

Larissa Lemos Mendanha Cavalcante[1]
Isis Maria Quezado Soares Magalhães[1]
Ricardo Camargo[1]
José Carlos Martins Córdoba[1]
Natalia da Silva e Lamas Mendes[1]
Marina da Costa Ribeiro[1]
Agenor de Castro dos Santos Moreira Júnior[1]

Abstract

Introduction: Hemoglobin (Hb) Taybe is an alpha globin chain variant (HBA2: c.119_121del p. Thr40del) characterized by the deletion of a threonine amino acid in codon 38 or 39 of the HBA2 (or HBA1) gene, initially described in Taybe (Israel). Such alteration originates from a structural abnormality and a highly unstable Hb with thalassemic characteristics, whose detection by conventional methods is laborious. Homozygous or compound heterozygous patients usually have chronic hemolytic anemia. In asymptomatic heterozygous patients, these variants are usually undetectable by electrophoretic methods. The objective of the study was to describe, in a case report, the rare variant of alpha globin identified in a pediatric patient, by molecular methods, through clinical findings incompatible with laboratory findings.

Objective: To describe the clinical, laboratory and molecular characteristics of a pediatric patient who is double heterozygous for Taybe variant hemoglobin and alpha globin gene deletion.

Method: Clinical-laboratory and hemoglobin alterations were detected in Neonatal Screening by conventional methods of hemoglobin electrophoresis. Peripheral blood samples from the patient and parents (collected by signing the TCLE) were sent to the Translational Research Laboratory of Children's Hospital in Brasilia, for clarification of the diagnostic suspicion. Confirmatory tests were performed by molecular PCR techniques, Sanger genetic sequencing and MLPA (Multiplex Ligation-dependent Probe Amplification) on genomic DNA extracted from peripheral blood leukocytes. Clinical data were obtained through electronic medical records.

Results: The male patient, infant at diagnosis, was initially referred with microcytic and hypochromic anemia unresponsive to iron, anisocytosis, with a hypothesis of alpha or delta thalassemia. HPLC examination of the patient and mother revealed, in both, decreased hemoglobin A2 (1.6% and 1.4%, respectively) and the presence of anomalous hemoglobin (HbB2 0.9% and 1.2%, respectively). Therefore, genetic sequencing was performed, which confirmed a point mutation in the delta gene (HBD: C.49G>C), which has no clinical repercussions. The parent did not show changes in the hemoglobin pattern or gene sequencing. The samples were submitted to the MLPA technique, which revealed the patient and mother as silent carriers of the alpha-thalassemic trait $-\alpha^{3.7}$After outpatient return, the patient presented hemolytic anemia and splenomegaly. Given the inconsistency between laboratory and clinical findings, alpha globin gene sequencing of the patient and parents was performed, which revealed the presence of the Taybe variant hemoglobin only in the patient, who did not receive the necessary blood transfusions for religious reasons.

Conclusion: According to the information in the database so far, the Taybe variant has not been reported in Brazil, suggesting that this case was the first in the country, particularly in the Federal District. The same aroused interest in hemoglobin alterations in HPLC, whose evaluation must be careful, as the co-elution of fractions can make identification difficult. Thus, the availability of more sensitive molecular techniques is essential for the correct diagnosis, especially in obscure ones, as they overload specialized care and often bring inconvenience to the patient and family. All the altered hematological findings can be explained by the fact that this variant is associated with alpha-thalassemia, even though it is a silent carrier.

Keywords: Variant hemoglobin. Alpha-thalassemia. Neonatal screening. Molecular diagnosis.

1. Hospital da Criança de Brasília José Alencar (HCB)

Nursing assistance in palliative care with children affected by Gangliosidosis GM1, an integrative review

Ronald da Silva Freitas[1]
Vinicius Abrahão Rodrigues

Abstract

Introduction: GM1 gangliosidosis is an inherited disease, due to the lack of an enzyme called beta-galactosidase, responsible for the breakdown of glycolipids known as GM1 gangliosides. Deficiency results in the accumulation of these glycolipids, causing progressive damage and leading to death. The most aggressive form of the disease has symptoms appearing between 3 and 6 months of age. Nursing care is fundamental and palliative care, defined by the WHO as care provided by a multidisciplinary team to improve the quality of life of patients and their families, is essential to provide relief from pain and other symptoms and attend to the humanistic perspective.

Objectives: Observe the need for protocols to better assist clients with neuro degenerative pathologies. Allow nursing to follow the principles of palliative care, seeking to relieve pain and other symptoms without hastening or postponing the death of the patient.

Methodology: This is a literary review of journals. Bibliographic search was performed in databases with a total of 8 articles that met the prerequisites to participate in this study: Latin American and Caribbean Literature in Health Sciences (LILACS), Health Information from the National Library of Medicine (Medline), Scopuse at Scientific Electronic Library Online (SciELO). A retroactive period of 10 years was used in the searches. The following descriptors were used: palliative care, gangliosis, patient comfort, family.

Results and Discussion: Nursing care in palliative care is necessary for children with GM1 Gangliosidosis, being a holistic approach that aims to improve the quality of life of the child and their family, relieving physical and emotional suffering. This care in pediatrics is a set of actions that aim to improve the quality of life of patients and their families through the prevention and relief of suffering in the treatment of symptoms, promotion of safety and psychological and social support. In summary, nursing care is essential for children with GM1 gangliosidosis as it aims to ensure the child's comfort, provide support to the family, monitor, and manage the complications of the disease, and guide the family to home care and preparation for death.

Conclusion: In this study it was possible to understand the importance of palliative care in the bio-psychosocial context with a holistic view. We can thus conclude that the role of nursing aims not only at care for the patient, but also with the binomial, promoting clinical improvement and providing an approach that aims at the best experience lived by the present family. It is evident that the nursing team plays an important role in the care of palliative patients, through comprehensive care that considers not only the physical dimensions of the disease, but also the psychological, social and spiritual dimensions.

Keywords: Palliative Care. Gangliosidosis. Mutation. Gangliosides. Patient comfort. Family.

1. Centro Universitário do Distrito Federal (UDF)

Letícia Cristina Alves do Nascimento[1]
Hévelin Silveira[1]

Abstract

Introduction: Evidence-based practice has stood out over the years to reinforce the importance of assistance and research to work together. The role of nurses has expanded, pointing to the need to act in the various areas that arise, seeking innovative scientific advances, in the cure of diseases or discovery of new drugs. The research area is constantly renewed, bringing with it new methods, equipment and discoveries. It can be observed that nursing has also adhered to new discoveries within the translational research system as technical knowledge. One of the reasons for this is the search to improve the quality of care provided and offer more safety to patients throughout the care process, during studies and experiences. An innovative field of research is translational research, the method of translation of knowledge, where scientific research in healthcare flows in two ways, joining knowledge between clinical and basic research. Combining nursing with translational research builds a more precise and necessary bridge between the researcher and the fields of practice. This correlation has been discussed since 1970 in the National Seminars on Nursing Research, where studies on how to incorporate such elements have been proposed. The incorporation of nursing benefits both the patient and the research professional, collaborating with the amount of understanding about health and disease to a molecular degree, and also helps in the process of caring for the individual who will be the main beneficiary from scientific progress.

Objectives: To show how relevant nursing practice is in the area of translational research, point out its various positive and pertinent effects, beyond the relevance of the intersection between intellectual knowledge and care practice.

Methods: Articles that mention the importance and benefits of nursing participation in the research area were studied, particularly those about translational research. The benefits for the patient were investigated when a nurse participates in the research process, besides the enrichment for all areas involved with the exchange of experience, scientific knowledge and the process of patient care.

Results: Since the 1970's, the idea of nursing being able to join translational research has been discussed, as well as the benefits and knowledge added as data of patient care and scientific data. Currently, the area is not yet fully merged with TP, but there are advances on such issues, as in 2005 when the Columbia-based School of Columbia-linked Nursing Research Society held its 17th Annual Scientific Session. Nursing research was defined as being an investigation related to nurses' knowledge and also nursing care

Conclusion: It was observed that nursing has much to add in the research area, despite social difficulties, the lack of trained professionals in the area, discrimination by many in the healthcare profession, and the long way to conquer rights on other topics. It expands the possibility of creating a bridge between molecular knowledge and the process of caring.

Keywords: Nursing. Care. Translational research.

1. Hospital da Criança de Brasília José Alencar (HCB)

The impact of therapeutic play in pediatric hospitalization

Jhénnyfer Stella da Silva Adriano[1]

Abstract

Introduction: During childhood, hospitalization may be present in the lives of children. For many years, health professionals have had difficulty deciphering, understanding, and connecting with the world of children, who are often subjected to invasive, painful, and stressful procedures. In this context, therapeutic play becomes a method used during hospitalization, in order to provide the child with a means of presenting the unknown, that is, to explain through play the procedures to which they will be submitted during their stay in the hospital, significantly reducing the damage caused during hospitalization. According to Tavares (2006), knowing that the fear of the unknown (fantasy) exceeds the fear of the known, if we think of reducing the unknown elements, we will probably reduce fear.

Objectives: This work aims to specify the main techniques of toys and games, such as the Therapeutic Toy, which is subdivided into Instructional, Dramatic or Enabling of Physiological Functions. We also conceptualize games such as make-believe or symbolic game, games in general, and dramatization, which become available tools for the practice of this therapy. In addition, we explain the main obstacles to its implementation in the hospital environment and the means to introduce the practice.

Methods: The method used in this paper is an integrative literature review, by means of articles from different platforms. The databases used to formulate the research were: MediLine, Scientific Electronic Library Online (SciELO), Virtual Health Library (VHL), Latin American and Caribbean Literature on Health Sciences (LILACS) and PubMed. The following health descriptors (DECS) were used: play therapy, therapeutic play, pediatric hospitalization, children and nursing. According to the inclusion criteria, the following were selected: electronic articles available in the above-mentioned databases, which discuss the performance of nursing to the patient in pediatric hospitalization, nursing performance in pediatrics, nursing care to the hospitalized child, which had full text with date of publication primarily between 2001 to 2022 and available in Portuguese and English. In the initial search, 40 articles were found, and of these, 20 were selected for critical analysis, because they had the relevant content for this research. The exclusion criteria were as follows: duplicate articles, those that were not pertinent to the proposed theme, those that did not contain relevant content for the proposed objectives and that were not complete electronically.

Results: After analyzing the articles, it was observed that with the insertion of therapeutic toys, the following results were obtained: reduced anxiety in both children and parents, the patient is more collaborative during the procedure and more comfortable to answer questions, with a greater sense of security; the toy also helps to express feelings, active participation of the child in the choices, humanization of care, among other benefits.

Conclusion: With this study we can state that the practice of techniques such as therapeutic play is essential for the child, since it reduces the various damages caused by hospitalization and helps to build the relationship between the professional, child, and family. Finally, we consider the importance of implementing the knowledge of these techniques as essential tools in the practice of care.

Keywords: Nursing team. Pediatrics. Playing. Hospitalization. Emotions. Communication.

1. Centro Universitário LS (UNILS)

Obesity in children and adolescents: treatments and perspectives

Ana Cecília Amâncio Vieira[1]
Thyago José Arruda Pacheco

Abstract

Introduction: Obesity is a serious public health problem that currently affects about 1 in 5 children and adolescents. Studies have shown that until 2030, about 250 million children and adolescents will be obese in the world. Problems such as obesity can affect a child's self-esteem, usually being the inception for disorders, causing anxiety and depression, in addition to several other health diseases. However, some alternatives can help to mitigate the effects of obesity.

Objective: The goal of this study was to find recent, scientifically based alternatives against obesity in order to apply them to children and adolescents.

Method: Literature review was carried out seeking alternatives to combat obesity and the consequences generated by it. All articles were searched from 2019 to 2023 in PubMed and the keywords used were: obesity AND physical activity OR depression, articles that were not written in English and did not have the mentioned descriptors were excluded for this review.

Results: Four articles were selected due to their high relevance and the current state of the art for the proposed objective. A 2019 article from Global Pediatric Health, another one from The New England Journal of Medicine, a 2022 randomized study presenting a systematic review with meta-analysis of the JAMA pediatrics, and the fourth being Guidelines from Pediatrics. The current literature shows that there are already effective treatments against obesity, but foremost, a risk assessment should be carried out and comorbidities should be treated. The administration of semaglutide (Glucagon-like peptide-1 receptor agonist), 2.4 g once a week, was one of the most promising treatments, reducing 5% of body weight in adolescents. In addition, the scientific pyramid top study of the JAMA pediatrics showed that physical activity can efficiently improve symptoms of depression that can be caused by obesity.

Conclusion: Therefore, in order to manage complex health problems like obesity in children and adolescents, it is possible to employ proven effective intervention measures. Semaglutide and changes in lifestyle are recent alternatives that can change the perspective of life and health of thousands of children and adolescents around the world, but not exclusively, as shown by the pediatrics guideline with several other viable alternatives based on the challenges of each one.

Keywords: Obesity. Semaglutide. Inflammation. Comorbidity. Pediatrics.

1. Universidade Católica de Brasília (UCB)

Ocular protocol in a child with cerebral palsy: case report

Mariana Ramos França Batista[1]
Ana Letícia de Sousa Oliveira[1]

Abstract

Introduction: Cerebral palsy is a set of disorders in posture and movement that causes numerous function limitations to the individual. Permanent neurological injuries that occur during growth or childhood, can cause serious damage to the nervous system. Strabismus is characterized as a dysfunction due to lesions in the subcortical oculomotor center and in the cerebellum which impairs the normality of binocular vision. Strabismus is found in children with CP.

Objective: In this mode, eye physiotherapy can decrease the degree of strabismus, through oculomotor exercises.

Methodology: This is a case study of a male child at the age of ten, carried out at the Community Service Center UniCEUB-Brasília in 2021. The evaluated purposes were visual acuity (Snellen's Table), degree of strabismus (Hirschberg test), cover test and ocular motility at the beginning and end of the ocular protocol.

Result: The child showed significant improvement in the degree of strabismus from 30° to 0° in the LE. Regarding the cover test, it showed a reestablishment of ocular alignment. Ocular motility developed a balance of the extrinsic musculature of the ocular system. In relation to visual acuity, there was no significant statistical difference.

Conclusion: Ocular physiotherapy is effective in the treatment of strabismus in children with Cerebral Palsy and in decreasing the degree of strabismus together with muscular rebalancing of the oculomotor system.

Keywords: Cerebral palsy. Strabismus. Ocular system. Ocular physiotherapy.

1. Centro Universitário de Brasília (UniCEUB)

Omalizumab for the control of severe asthma and quality of life for children and adolescents at a tertiary hospital

Carmen Lívia Faria da Silva Martins[1]
Mirella Nunes Cunha Souto

Abstract

Introduction: In general, about 30 to 80% of pediatric asthmatic patients start to show symptoms during the first three years of life. Asthma affects approximately seven to 10% of the population. The estimated average global prevalence of asthma is 11.6% among schoolchildren (six and seven years old) and 13.7% among adolescents (thirteen and fourteen years old). Omalizumab (anti-IgE), a low-dose oral corticosteroid used directly in asthma with a Th2 profile, is the only one of its kind found in the Brazilian market and recommended by GINA. Evaluating the efficacy of Omalizumab in the treatment of children and adolescents with severe allergic asthma, followed up at the referral clinic of the Hospital da Criança in Brasília José Alencar helps understand the use of the medication and improving the quality of life of patients with this condition.

Objective: To evaluate the efficacy of Omalizumab in the treatment of children and adolescents with severe allergic asthma, followed up at the referral clinic of the Hospital da Criança in Brasília José Alencar.

Method: This is an analytical study of a cohort of children and adolescents with severe allergic asthma followed up at the referral clinic of the Hospital da Criança of Brasília José Alencar (HCB), from September 2019 to January 30, 2020. Pediatric patients, followed up at HCB, aged over 6 years and diagnosed with severe allergic asthma, using a high dose of inhaled corticosteroid alone or in association with long-term bronchodilator were included.

Results: Our study included 14 patients who met the inclusion criteria, 50% female and 50% male. With the general average age of patients being 11 years and 7 months (6 years to 17 years), the predominant age group among patients was 11 to 13 years (57.14%).

Conclusion: After conducting the present study, we concluded that Omalizumab proved to be efficient in the treatment of children and adolescents with severe allergic asthma, followed up at the referral outpatient clinic of the Hospital da Criança in Brasília José Alencar, with a decrease in the number of exacerbations, hospitalizations, visits to clinic and improvement in patients' quality of life. Omalizumab controlled severe asthma symptoms in pediatric patients.

Keywords: Severe asthma. Omalizumab. Pediatrics. GINA. ACT.

1. Hospital da Criança de Brasília José Alencar (HCB)

Orofacial myofunctional aspects of individuals with genetic syndromes

Laura Davison Mangilli Toni[1]
Andreza Soares Maia
Max Sarmet Moreira Smiderle Mello

Abstract

Introduction: Multidisciplinary work and advancements in healthcare have increasingly aroused interest in Speech Therapy and Genetics, as they evolve as complementary sciences, not only for better understanding of human communication and its disorders, but also for better characterization and development of specific programs for carriers of genetic syndromes. The role of the speech therapist, as a member of the multidisciplinary team, is to identify the manifestations involving language, speech, hearing and voice, as well as the functions of the stomatognathic system (SS).

Purpose: To characterize the orofacial myofunctional aspects of individuals with genetic syndromes by analyzing the clinical evaluation of patients referred to speech therapy team at hospitals in the Federal District.

Methods: This is a cross-sectional and descriptive study. We evaluated 38 patients, both genders, aged between three months and thirteen years, using the Myofunctional Orofacial Evaluation Protocol with Expanded Scores, Clinical Evaluation Protocol for Pediatric Dysphagia and Dysphagia Risk Assessment Protocol, in order to characterize orofacial myofunctional aspects in an applied manner.

Results and Discussion: the presence of alterations in greater incidence in the orofacial myofunctional aspects related to the lips, tongue, mandible/maxilla ratio, hard palate and cheeks was observed. As for mobility of structures in relation to the lateralization movement, swallowing, and breathing changes in varying degrees, mastication was the function that presented the least inadequate aspects. The alterations identified in this study, which add information to the existing scientific base, indicate that the orofacial myofunctional system of individuals with genetic syndromes is altered in terms of structures, mobility and functions, with variable impairments, which do not prevent their oral feeding in most cases.

Conclusion: Orofacial structures presented relevant postural inadequacies in cheeks, tongue, lips, hard palate and mandible/maxilla relationship, characterized by aspects of increase or decrease in the tonicity of these organs. The mobility of the lips, tongue, mandible and cheeks indicated that the lateralization movements presented alterations in all the evaluated structures, with a higher degree of incidence. The mandible was the structure that presented the most mobility problems, on the other hand, it was the one that presented the least changes in appearance and posture. Swallowing alterations were identified in varying degrees in part of the sample, mild oropharyngeal dysphagia was the most frequent, being the functionality that showed more characteristics of inadequacies. Breathing evidenced the incidence of alterations to its performance, presenting aspects of light and moderate oronasal breathing. In mastication, the aspects of masticatory pattern were the most recurrent alteration, the function that presented the least aspects of alterations.

Keywords: Syndrome genetics. Stomatognathic system. Swallowing. Speech therapy.

1. Universidade de Brasília (UnB)

Patient and family centered care: perception of parents of children with complex chronic conditions

Marina Rehem Póvoa Braule[1]
Natan Monsores de Sá
Carolina Almeida Suassuna
Denise de Lima Costa Furlanetto
Lisandra Parcianello Melo Iwamoto
Natalia Marques de Almeida

Abstract

Introduction and Objectives: The present pilot study had the objective of knowing the perception of parents and caregivers in relation to patient and family-centered care for children with Complex Chronic Conditions (CCC) by. The term 'chronic conditions' encompasses the integration of chronic diseases, infectious diseases, and some disabilities, which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by non-reversible pathological change, require special patient training for rehabilitation, may require a long period of supervision, observation or care that permeates all levels of the health system. These children have a life that revolves around hospitals and other health units, and therefore, humanized care is of paramount importance so that both patients and their families feel welcomed and cared for by the health team, as they go through periods of clinical exacerbation and are hospitalized for long periods.

Methodology: This is a longitudinal study with a multimethodological approach, in which a questionnaire was applied to parents and caregivers of children with CCC that agreed to the informed consent form, and then answered questions that encompass both socio-economic aspects and the relationship between families and the health team, and vice versa. The instrument used was Perception of Family-Centered Care – Parents (PFCC-P Brazilian version), with which 22 responses were obtained and after descriptive analysis, it was found that, for the most part, parents and guardians feel welcomed and respected by the care team, participate in their child's care and treatment decisions, are always able to ask questions about the treatment carried out, their privacy and confidentiality regarding their child's information are always respected, but the other family members are not always able to visit and be included in the care. Rotation of the care team was observed, and new staff were not always aware of the family situation and the child's individual needs.

Results and Conclusion: Based on the analysis, it is possible to perceive a relationship between parents/guardians and the health team, a not-so-fruitful relationship with the family members, and that the team is not always aware of the family situation and the child's individual needs, but they provide guidance on care and are available to help whenever necessary. The instrument proved to be feasible to observe the quality of the relationship between parents and caregivers with the professionals of the multidisciplinary team, therefore it can be used in other clinical contexts for the same purpose, as well as for the Brazilian National Census of Rare Diseases.

Keywords: Hospitalized adolescent. Hospitalized Child. Family. Healthcare models. Healthcare personnel.

1. Universidade de Brasília (UnB)

Perspectives on treatment with car-t cells for leukemias in children: a literature review

Vitória Maria Xavier Silva[1]

Abstract

Introduction: The Food and Drug Administration (FDA) approved Chimeric Antigen Receptor T cells (CAR-T) for treating relapsed or refractory leukemias. Since the CAR replaces its TCR component, CAR-T cells have high specificity and can recognize cell surface molecules without expressing the human leukocyte antigen (HLA). The CAR has two domains: one extracellular and one intracellular. The variation of the extracellular domain allows for the specificity of the treatment, modifying the affinity of the T lymphocytes for the recognition of a specific antigen on the surface of a cell. The disease may recur despite treating leukemia in children with therapies that provide significant curative potential. Thus, the fight against this cancer has highlighted the need to intensify more promising alternatives, which have improved selectivity to destroy cancer cells. Here come CAR-T cells, which have demonstrated effectiveness in children and young adults.

Aim: This work aims to explain, based on recent literature, state of the art in the treatment of CAR-T cells, showing what has maximized the success of this immunotherapy.

Method: This is an exploratory qualitative review carried out with an active search in the PubMed database, using the descriptors 'Leukemia and Childhood and Immunotherapy adoptive '. Nine English, Spanish, and Portuguese articles from the last six years were selected.

Result: As analyzed, for a better implementation of adoptive immunotherapy, studies suggest the association of CAR-T cells with the immunomodulatory lenalidomide, which improves immune synapses between Chronic Lymphocytic Leukemia (CLL) and T cells, preventing increased expression of B7 and TNF receptor families of transmembrane inhibitory molecules. In addition, the use of Bruton's tyrosine kinase inhibitor, ibrutinib, decreases the expression of PD-1 in T cells and significantly increases the expansion of CAR-T cells in vivo, preventing the depletion of T lymphocytes and, consequently, there is the high expression of transmembrane inhibitory receptors, including CTLA-4, PD-1, and LAG-3. Immunotherapy presents side effects in the range of medical management, such as cytokine release syndrome (CRS). Immunosuppressants such as tocilizumab control CRS without compromising the immunotherapy. Severe neurotoxicity is one potential side effect of immunotherapy, which still does not show a clinical pattern for management. Despite the side effects, a clinical trial at the Children's Hospital of Philadelphia with 25 pediatric patients with Acute Lymphoblastic Leukemia type B showed complete remission of 90% within one month, demonstrating the strong potential to destroy malignant cells through T cells.

Conclusion: Observing the encouraging results presented by immunotherapy with CAR-T cells, the importance of encouraging new research directed to the area becomes evident since, in addition to presenting quite favorable rates of complete and partial remissions in relapsed or refractory leukemias and therapeutic potentials of significant impact for the success of the therapy, the consequences presented by the treatment are of a possible reversal, with the proper monitoring of pediatric patients.

Keywords: Leukemia. Childhood. Immunotherapy adoptive.

1. Universidade Católica de Brasília (UCB)

Aline Bezerra de Melo Filter[1]
Beatriz Eler de Lima
Ana Cecília Amâncio Vieira
Ana Luísa Ayres Delduque
Clara Alice Yet Félix Silva
Erica Beatriz dos Santos Mützenberg

Abstract

Introduction: Pediatric palliative care was conceptualized by the World Health Organization in 1998 as active and full care provided to children with life-limiting or life-threatening conditions, which should be offered regardless or not of the existence of a curative treatment. Hence, palliative care requires a multidisciplinary team, with qualified healthcare professionals trained to use new technologies, in order to enable the continuity of life, in addition to preventing and alleviating the child's suffering. One of the new methodologies used in palliative treatment is music therapy, a treatment resulting from the combination of art and healthcare, which aims not only at benefiting patients with difficulty in expressing their emotions, as they are still in psychosocial and emotional development, but also at facilitating communication and relationships between health professionals and pediatric patients.

Objective: The objective of this summary is to evaluate the positive effects of inserting musical dynamics in pediatric palliative care.

Methodology: For this purpose, the literature review of academic articles from the SciELO and PubMed databases was used as a method, using the following descriptors: 'pediatrics,' 'palliative care', 'music therapy' and 'multidisciplinary team'. Articles published between 2018 and 2022, in English, Portuguese or Spanish, were used as inclusion criteria. Articles focusing on therapies in adults or on other methods of palliative therapy were excluded from the selection.

Results: This scope review resulted in the perception that, due to the inclusion of music therapy in pediatric palliative care, there was an improvement in the ability to express and deal with feelings of loneliness and longing for family ties in the hospital environment, which increases adherence to treatment and contributes to reducing the patient's pain. Thus, the non-pharmacological care treats physical and emotional symptoms in a playful and innovative way, in addition to generating a bond of trust between the multidisciplinary team and the pediatric patient's family, which is an important part of improving care.

Conclusion: Finally, it is concluded that there is a correlation between the evolution of palliative care and the adoption of music therapy, seeing that it improves the process of emotional development and pain control of the child, the communication between the multidisciplinary team and the patient, the decrease in the rates of abandonment of care terminals and the patient's quality of life. Therefore, new studies are needed to expand the scientific production on the subject as well as to disseminate scientific evidence that refers to the clinical practice of music therapy as an active agent in pediatric palliative care treatment.

Keywords: Pediatric. Palliative care. Music therapy. Multidisciplinary team.

1. Universidade Católica de Brasília (UCB)

Post-Covid-19 psychotic outbreaks in pediatrics and hebiatrics: what to expect

Letícia Mello Matos[1]
Raquel Rodrigues Fonseca da Cunha
Luana de Oliveira Pires
Clarice de Abreu Pereira
Ana Carolina Borges Penalva Ferreira
Ingrid Reis Abrante
Julia Silva Vasques
Carlos Aucélio

Abstract

Introduction: according to data provided by the World Health Organization, more than 25% of the pediatric population has been infected with COVID-19 since the virus was identified. As a new pathology, numerous studies have been carried out to understand it and reduce harmful effects as much as possible. Unfortunately, with children and adolescents being mostly asymptomatic, the group relied on less forceful efforts in prevention of the disease, which already shows psychiatric consequences. Mania, anxiety, and emotional dysregulation were the onset of neuropsychiatric manifestations after infection with SARS-CoV-2. Furthermore, theme's choice was based on the relevance of the subject in a post-pandemic context.

Objective: The study aims to affirm the correlation between psychotic outbreaks in pediatric and hebiatric patients and post-infection with the new coronavirus, in addition to present possible psychiatric perspectives for this population group.

Method: the terms 'Psychotic Disorders' 'COVID-19', 'Child Psychiatry' and 'Infectious Disease Medicine' were searched on the scientific platforms PubMed, Lilacs and Scielo. No time frame was performed. Finally, 6 articles were selected for this review.

Results: Despite having a lower risk of developing severe cases of COVID-19, children and adolescents suffer from consequences of the pandemic, from problems generated by the virus in the body to those associated with the stress caused by changing routines. In cases of problems directly linked to the virus, it has been observed that pediatric patients can suffer different forms of cognitive, behavioral and perceptual symptoms after periods of subsequent infection. Cases have been observed in which the immune response to this virus, mediated by intrathecal antineural autoantibodies, resulted in autoimmune psychosis, acute psychosis and even loss of speech and movement. A case of psychosis indirectly linked to the virus was observed, in which the patient, after a mild case of COVID-19, presented mixed signs and symptoms of anxiety, coursing with panic attacks associated with psychotic episodes. Cases like this have a multifactorial etiology, resulting from a complex interaction between systemic and cerebral inflammation and environmental stress in vulnerable individuals, requiring longer follow-up to observe the neuropsychiatric evolution. Furthermore, among the indirect consequences of the pandemic, there is also an increased risk of depression in the short term or its manifestation up to 9 years after the stress generated by the changes imposed by the pandemic.

Conclusion: Acute psychiatric manifestations with the possibility of chronification are understood as a complication of SARS-CoV-2 infection in the pediatric and hebiatric population, showing the need for prevention against the new coronavirus, even though this portion of the population is currently asymptomatic. Finally, in the case of a recent pathology, it is necessary to carefully observe the ones who have had contact with the virus to reduce the intensity of possible neuropsychiatric complications of the disease and guarantee a better quality of life for these patients. In the future, the microdosing of psychedelics for refractory depression in adolescents may contribute to studies and even resolutions about psychotic outbreaks after infection with the new coronavirus from the action of psilocybin on the nervous system.

Keywords: Psychotic Disorders. COVID-19. Child Psychiatry. Infectious Disease. Medicine.

1. Universidade Católica de Brasília (UCB)

Primary care in triple border and challenges for the comprehensive care of children with special healthcare needs

Gabriela Dominicci de Melo Casacio[1]
Gabriela Gomes Espindola
Adriana Zilly
Débora Falleiros de Mello
Rosane Meire Munhak da Silva

Abstract

Introduction: To deal with community health problems and ensure comprehensive care, Primary Health Care (PHC) acts as a gateway and involves four main attributes: first contact, longitudinality, comprehensiveness and coordination. Comprehensive care, in turn, comprises important elements that ensure resolution and reduce inequities and risks to population health, especially from more fragile groups such as Children with Special Health Care Needs (CSHCN). However, the challenges to ensure comprehensive care are more evident in vulnerable regions, such as international borders. The lack of immigration control, the high demand of the foreign population for Brazilian health services and the absence of inter-country agreements generate overload and disarticulation of services, which increase obstacles to care.

Objective: To understand the care offered by primary care services of an international border municipality for children with special health needs.

Method: Qualitative study, based on hermeneutic-dialectic methodology and elements of comprehensive care. The study included nurses from PHC units in Foz do Iguaçu, a city on a triple border region (Brazil-Argentina-Paraguay), Paraná, Brazil. In-depth interviews were conducted, with a semi-structured script and triggered by a guiding question. The deductive thematic analysis was chosen, establishing a dialectical relationship with the attributes of PHC and the elements of comprehensive care. This study was approved by the Ethics Committee in 2020.

Results: The interviews were conducted with 15 nurses from 11 PHC units in the north,

south, east, west, and northeast regions. Four main categories emerged: challenges to access in primary healthcare frailties in bonding and interaction over time lack of integral attention to recognizing problems and obstacles to coordination of care.

Conclusion: The absence of public policies aimed at the health of the cross-border population and fragilities of the essential attributes of primary care impaired comprehensive care and reduce the assistance of CSHCN. In order for children to achieve comprehensive care, continuity of care and resolution for their health problems it is essential to consolidate an adequate articulation between the border countries and strengthen the essential attributes of PHC, making access less bureaucratic and more effective, with guidance on the flow of care, as well as welcoming and establishing lasting links with community.

Keywords: Primary healthcare. Disabled child. Child health. Border health. Qualitative research.

1. Universidade de São Paulo (USP)

Quality of life for mothers of technology-dependent children in a pediatric intensive care unit

Brendo Vitor Nogueira Sousa[1]
Aline Oliveira Silveira
Elenilda Farias de Oliveira
Gisele Martins

Abstract

Introduction: Technology-dependent children are those who need medical-hospital devices, such as tracheostomy, mechanical ventilation, gastrostomy, nasogastric/enteral and/or bladder tubes, among others, specialized multidisciplinary monitoring for rehabilitation and maintenance of life. These children have a variable level of impairment and may be dependent on low or complex technologies to meet their needs. This context calls for someone who takes on the necessary care and follow-up, responsibilities which have an impact on family functioning, especially on the life of the person who has the role of primary caregiver.

Objective: To evaluate the quality of life of the primary caregiver of technology-dependent children in a Pediatric Intensive Care Unit.

Methodology: This is a quantitative survey, carried out in a public Pediatric Intensive Care Unit in the Federal District. For data collection, the sociodemographic questionnaire prepared by the researchers and The World Health Organization Quality of Life abbreviated, translated and validated for the Brazilian reality were used. For data analysis, descriptive statistics, frequency distribution and application of tests such as Spearman Correlation, Kruskal-Wallis and Mann-Whitney were performed.

Results: The study included 21 main caregivers of children with an average length of stay of 30.24 days (SD: 54.29). The data show the mother as the main caregiver relative (100%), with a mean age of 31.86 years (SD: 6.97), living in stable or married relationship (76.19%), with high-school level education (47.62%), unemployed (47.62%) and with low income (52.38%), receiving some assistance from the federal government (71.43%). Regarding quality of life, a low total quality of life score stands out according to the analyzed domains (Average: 43.58, SD: 10.37), with more accentuated rates in the social domains (Average: 32.54, SD: 22.50) and environment (Average: 42.56, SD: 9.95), directly influenced by education (p-value: 0.035) and income (p-value: 0.017).

Conclusion: The study reveals data of epidemiological and social importance, as the low quality of life of mothers of technology-dependent children is perceived in several aspects, which is enhanced in the context of prolonged hospitalization.

Keywords: Child health. Chronic disease. Quality of life. Family.

1. Universidade de Brasília (UnB)

Remodeling of the work processes of the contract area as a tool for the implementation of organizational improvements: experience report

Joseete Mendonça Mesquita dos Anjos[1]
Helen Cristina Araújo Cardoso Silva

Abstract

Introduction: The acquisitions and contracts made by ICIPE for the sake of HCB are governed by the rules of civil law, applying to them, in supplely, the principles of the General Theory of Contracts and the provisions of private law. During the contractual life cycle, understood from the beginning of the validity of the instrument until its closure, several activities must be performed by the employees involved in the technical and administrative management of the same. In this context, the format of contract management adopted by HCB /ICIPE is a determining factor to achieve the goals that fit it within the Unified Health System.

Goal: Describe the process of remodeling the monitoring of contracts in a tertiary pediatric hospital of SUS-DF under management of a non-profit social organization, with a view to identifying its main gaps, analyzing the critical success factors regarding contract management, and suggesting the introduction of improvements aimed, in particular, at identifying contractual risks, in order to support decision-making aligned with the established strategic planning.

Method: Analysis of process tracking type experience through documental analysis and participant observation in the period 2019 to 2022.

Results: The reported experience focused on detailing internal issues related to the execution of contract work processes and technology transfer, covering the highlight of the intersections with the processes performed by the various areas of the hospital involved, survey of their strengths, weaknesses, and introduction of improvements in the work processes translated into the new flowcharts. The experience was described in three phases: a) the context of contract management by the social health organization (OSS), b) remodeling of the Contract Sector, and c) coordination and monitoring of the implementation of new flows.

Conclusion: The understanding of existing workflows resulted in greater interaction between the technical team and other employees involved in the management and contractual supervision and allowed the identification and proposition of solutions to reduce existing bottlenecks, especially regarding the monitoring and evaluation of contractual management controls and co-responsibility of those involved. For effective management of changes in the activities of the sectors it is necessary to optimize the use of available technological resources aiming at standardization and consolidation of activities and data analysis and evidence-based decision making.

Keywords: Public health. Organization and administration. Contracts.

1. Hospital da Criança de Brasília José Alencar (HCB)

Savings generated in contracting processes in a social organization managing a public, pediatric, and tertiary hospital in the Federal District

Leandro Pereira Bias Machado[1]
Renato da Silva[1]
Aline Silva Santos[1]
Raimundo Nonato Quaresma[1]
Sammea Emanuelle Cordato Bruschi[1]
Stephany Vieira Coelho[1]

Abstract

Introduction: The negotiation is a stage in which the parties, who agree on common and antagonistic interests, meet to analyze proposals to reach a satisfactory agreement. In the Federal District, the process of hiring and acquiring social organizations with treasury resources is regulated by Decree No. 33,390 of December 6, 2011. The decree, in its article 2, item VII, allows the execution of a negotiation stage in the processes executed with public resources to maximize results in terms of quality and price.

Objective: Identify and quantify the percentage of reduction conferred by the negotiation phase and the market search extension stage in service and procurement contracting.

Method: This is a descriptive survey of data from the negotiation stage between January 2022 and December 2022 in a pediatric, public, and high-complexity hospital in the Midwest, managed by a social organization. The data were collected using the APOIO COTAÇÕES® system, allowing the evaluation of the procurement process extract, the records of the products" values in the first quotation, and after the conclusion of the negotiation/market search stage.

Results and Discussion: During the analyzed period, 588 processes were identified with the analyst's actions to reduce values. Of these, 6% (35) were service related, and 94% (553) were item acquisitions. When the success of the negotiation was evaluated, 55.95% of the processes had a price reduction after the analyst's contribution. The performance generated a reduction percentage in price values of 4.1% in the period, which corresponded to an accumulated annual savings of R$ 3,197,608.21.

Conclusion: In the period, there was an economy of 4.1% of the total annual contract value, with an effectiveness rate in the negotiation process of 55.95% of the attempts made. The percentage of savings is substantial, contributing to the institutional financial sustainability, making the procurement process effective, and with a return on the use of resources saved in the maintenance of services to the population, since it is a nonprofit institution and 100% of its services are provided by the Unified Health System.

Keywords: Negotiating. Social Organization. Process assessment. Unified health system.

1. Hospital da Criança de Brasília José Alencar (HCB)

Skin lesion related to the use of central catheter in post-surgical newborn of gastroschisis correction: case report

Carolina Tenfen[1]
Rosane Meire Munhak da Silva
Grasiely Masotti Scalabrin Barreto
Ana Paula Contiero Toninato
Adriana Zilly

Abstract

Introduction: Gastroschisis is a malformation of the abdominal wall of the fetus that is not completely developed and allows part of the intestine and other organs to be exposed to the amniotic fluid and, subsequently, to the postpartum environment, without protection. For the treatment of this malformation, there is a need of surgical procedure and other invasive procedures to support the recovery of the newborn.

Objective: To report a case of severe skin injury caused by the use of a central catheter in a newborn subjected to surgical correction of gastroschisis.

Method: Report of a case experienced in a multiprofessional neonatology residency, in 2022 and 2023, at the University Hospital in Western Paraná, reference for high-risk care. The study had approval from Committee of Ethics.

Results: 35-week-old newborn, male, Apgar score 3 and 7, weighing 2.450 kg, diagnosed with gastroschisis still in pregnancy. Mother with a 12 hour of rupture of membranes was subjected to surgical delivery. At birth, the baby was intubated and manually ventilated and sent to the neonatal intensive care unit. For the care of bowel loops, these are hydrated with 0.9% physiological sodium chloride and wrapped in sterile plastic. In neonatal unit, the baby was kept sedated and with ventilatory support. Immediately afterwards, he had with a peripheral central catheter inserted, started intravenous hydration, and was sent to the surgical center for the first procedure in the first hours of life. The 2nd surgical procedure was performed at 30 days of life, and the 3rd at 45 days. Newborn evolved with severe sepsis (due to Candida albicans, Staphylococcus epidermidis, Klebsiella pneumoniae, Pseudomonas aeruginosa), liver disease, cholestasis, severe malnutrition, frozen abdomen, suture breakdown of the surgical dehiscence. After 49 days of life, it was necessary to perform a phlebotomy in the right subclavian vein due to the impossibility of passing the peripherally inserted central catheter due to severe edema, bruising and lack of catheter progression. The surgical wound presented phlogistic signs and suture wound, with drainage of purulent and smelly secretion in great quantity. As well as the surgical wound, the insertion of the central catheter (phlebotomy) evolved with drainage of secretion of yellowish coloration in great quantity, without fetid odor. Thus, the insertion of the phlebotomy requires numerous dressings wounds daily, using various materials, which were: transparent film, catheter fixator, sterile swab for insertion at the ostium, polyurethane foam, and protective spray. All these strategies had the objective of greater durability of the dressing, given that cold skin, hyperemia, and the fact that with each change of dressing new lesions arise. The baby evolved to death at 59 days of life, due to multifactorial causes, especially sepsis.

Conclusion: The polyurethane foam was to be the best strategy used to protect the skin and promote comfort. The peculiar physiological conditions of the newborn would constitute an important barrier for the proper handling of the product, generating doubts and increasing the concerns that act in direct care in neonatology.

Keywords: Newborn. Skin. Neonatology. Nursing.

1. Hospital Universitário do Oeste do Paraná (HUOP)

STAT 3 gain of function mutation in a CIVD phenotype patient

Gabriella A. Gaia Duarte
Maria Clara M. de Carvalho
Ísis M. Quezado Magalhães[1]
Stephan Ehl
Cláudia França C. Valente[1]
Fabíola Scancetti Tavares[1]
Karina M. de Melo[1]

Abstract

Introduction: Common variable immunodeficiency (CVID) is an inborn error of immunity or primary immunodeficiency disease characterized by repeated infection associated with hypogammaglobulinemia. Monogenic causes of CVID sometimes can be determined. Recently, variants within the gene encoding the transcription factor STAT3 were associated with monogenic CVID. The signal transducer and activator of transcription 3 is a key transcription factor involved in the regulation of immune cell activation and differentiation. Recent findings highlight the role of germline activating STAT3 mutations in inborn errors of immunity characterized by early-onset multiorgan autoimmunity and lymphoproliferation.

Objective: Report a clinical case of hypogammaglobulinemia and life threatening autoimmune hemolytic anemia with identified STAT 3 GOF mutation.

Methodology: Data were collected from electronic medical records.

Results: The report involved an 18-year-old female patient who presented, 5 years later, asthenia, pallor, abdominal pain, vomiting, diarrhea, and hepatosplenomegaly. She was referred to hematology and began follow up of hemolytic anemia with poor response after several courses of corticosteroids. She was subsequently referred to the HCB immunology service for evaluation of the immune system which showed, in addition to hemoglobin 5.3g/dL, Coombs Direct positive, immunoglobin levels beyond expected for age (IgG 193 mg/dL, IgA 22 mg/dL, IgM 13.2 mg/dL) confirmed a common variable immunodeficiency phenotype. Rituximab was initiated in a severe episode of hemolysis, but patient developed anaphylaxis with medication. Desensitization was performed, although the expected clinic response was not obtained. She had presented pneumonias and several episodes of gastroenteritis, one complicated with sepsis and needed intensive care. Double negative T cells was carried out to investigated Autoimmune Lymphoproliferative Syndrome with normal results. Bone marrow biopsy was negative for neoplasia. The next step for treatment was splenectomy, but with an effort a Next Generation Sequencing panel for primary immunodeficiency was performed and detected heterozygous mutation [c.1082A>G: p. (Gln361Arg)] in STAT 3 gene, a variant of uncertain significance (VUS) that was tested in vitro and confirmed the behavior as a GOF mutation. Patient is clinically stable with continued use of cyclosporine.

Conclusion: These data complement previous studies in which germline STAT 3 activating mutations can lead to the development of pathological phenotypes such as the case described here. It also reinforces the importance of genetic testing in clinical practice, enabling more accurate diagnoses and targeted therapies.

Keywords: Primary immunodeficiency diseases. Common variable immunodeficiency. Hypogammaglobulinemia. STAT 3 transcription factor.

1. Hospital da Criança de Brasília José Alencar (HCB)

Caio Toscano Lessa[1]
Ana Beatriz Caetano Santos de Sá
Ana Clara Monte Varandas
Ana Clara Moreira Almeida
Beatriz Eler de Lima
Helena Monte Varandas
Pedro Augusto Goncalves dos Santos

Abstract

Introduction: Artificial Intelligence (AI) has significantly improved in recent years in cancer diagnosis, tumor classification, and treatment optimization in the field of adult oncology. However, pediatric oncology presents challenges that hinder the successful use of AI. The use of AI has the potential to improve patient outcomes in the field by aiding in diagnosis and treatment management.

Objective: The objective of this review is to evaluate the current applications of AI systems in pediatric oncology and their limitations.

Methods: On March 11, 2023, an electronic search was conducted in the PubMed platform, using the following search words: medical oncology, children, and Artificial Intelligence. Only reviews, systematic reviews, and clinical trials published in the last five years were considered. An age filter was applied to select articles about children from birth to 18 years old. The search resulted in 11 articles, and after the screening, 4 articles within the scope of this review were selected.

Results: Through the collection of quantitative data on a microscopic scale, AI models can detect changes that are impossible for humans to notice in image exams, facilitating cancer diagnosis through quantitative analysis. Although this application is still in the early stages of development in pediatric oncology, it is promising for the future of the field. Additionally, AI has been successfully used in predicting the outcome of children with cancer better than traditional models based on a statistical analysis of similar cases. Nonetheless, the use of AI in pediatric oncology currently has limitations, as childhood cancer is rare, and this scarcity limits the available data to train AI models, which affects the proficiency of such systems in pediatric cancer contexts. Another challenge is the variation in data formats and data types through different studies in the field, which severely limits the use of such models. However, the Childhood Cancer Data Initiative from the National Cancer Institute is standardizing data from multiple studies, which will have a profound impact on training better AI systems for application in childhood cancer improving accuracy and reliability.

Conclusion: The use of AI systems in pediatric cancer holds great potential for predicting and improving patient outcomes. However, the challenges of data collection and standardization are significant and must be addressed to develop better AI models. Future studies should focus on applying AI specifically for cancer diagnosis and treatment in a pediatric setting. While AI has shown success in adult oncology, it still has a long way to go before it can be used successfully and on a large scale in pediatric oncology.

Keywords: Children. Medical oncology. Artificial intelligence.

1. Universidade de Brasília (UnB)

Supportive therapy in children with spinal muscular atrophy: a multiprofessional perspective

Luiz Felipe Neves Frazão[1]
Antonio Muniz da Silva Neto
Darllen Saluana Ribeiro Peixoto
Fernanda Cândida de Araújo Molinero
Gabriel Rodrigues Vargas
Francielle Andrade Carvalho Rosa

Abstract

Introduction: Spinal muscular atrophy (SMA) is a neuromuscular pathology of genetic origin, resulting from progressive muscle weakness. It is caused by hemostatic imbalance and breakdown of the fundamental motor neuron protein, by changes in the decoding of the SMN-1 gene, evident in chromosomes 5q13. According to Brasil (2020), in the Brazilian territory, 20,459 deaths were reported in a 24-year interval, with an incidence of 1:6,000 to 1:10,000 births. Furthermore, it consists of a rare and incurable condition that affects the quality of life of patients, in the social context, due to progressive limitations. After all, this condition encompasses the support therapy responsible for prolonging and improving life, through multidisciplinary techniques, of those affected, given the search for introduction in a social context.

Objective: To understand the main concepts about multiprofessional palliative care in pediatric patients with SMA.

Methods: This is a narrative review of the literature, in which the Medical Literature Analysis and Retrieval System Online (Medline) and Scientific Electronic Library Online (SciELO) databases were used, obtaining 1,760 articles. Of these, 1,755 works were excluded due to inadequacy to the central theme, full unavailability, or for being research funded by pharmaceutical industries. Five articles were selected, in English and Portuguese, published between 2019 and 2022. These descriptors in Health Sciences (DeCS) were used: spinal muscular atrophy, palliative care, multiprofessional team, pediatrics.

Results: The research showed that, due to the difficulty of the diagnosis, even with modern technologies, there are no therapies with a total curative character for AME, but rather palliative managements that aim to reduce the consequences that this disease generates in children. SMA originates from the decoding, within chromosome 5q13, of the SMN-1 gene, responsible for the synthesis of the SMN protein, essential for motor neuron functioning. This muscle denervation corroborates painful and exhausting prognosis for patients, given the need for supportive therapy and the psychosocial conditions of children, as they lose muscle, breathing and swallowing capacity, resulting in an assisted and limited life. Complications are related to disabling conditions, such as: risk of developing pneumonia, chronic pain, malnutrition due to reduced energy consumption and muscle weakness. These scenarios can be alleviated with the help of multidisciplinary teams composed of physiotherapists, occupational therapists, orthopedists, nutritionists, who are of paramount importance for the prevention of clinical conditions, improving and prolonging the well-being of patients. In addition, the insertion of parents in the therapeutic environment is essential, as the pediatric patient demands special attention and care. Their connections go beyond simple presence, to affection and reciprocity.

Conclusion: Describing SMA proved that, due to the pathological sequelae and pathophysiological mechanisms, the high death rate is justified. The irreversible consequences are evident, mainly in the psychosocial nature of the child. As primordial pillars in management, multidisciplinary attitudes are essential. Because they develop the extension and improvement of the quality of life of the patient and his family. However, raising awareness about SMA in the population and creating government support networks for those affected are attitudes that can impact the health of these individuals and social introduction.

Keywords: Spinal muscular atrophy. Palliative care. Multiprofessional Team. Pediatrics.

1. Universidade de Rio Verde

Raquel Rodrigues Fonseca da Cunha[1]
Letícia Mello Matos
Rita de Cássia Mello Matos

Abstract

Introduction: In a hospital environment, technology has introduced new equipment, treatments, and techniques to neonatal care, contributing to the decrease in the mortality rate in this group and, consequently, to the increase in their survival. In addition, technology helps to build and disseminate knowledge that underlies different ways of caring, and also offers support and education outside the traditional clinic environment, contributing to the reduction of early breastfeeding abandonment.

Objective: The present study aims to reiterate the importance of the involvement of health professionals with the virtual environment, owing to the search for information by patients, especially lactating women, with doubts about breastfeeding.

Method: The terms 'Breast Feeding,' 'Neonatal,' 'Technology' and 'Postpartum Period' were searched on the scientific platforms PubMed, Lilacs and Scielo, in accordance with the descriptors extracted from the DeCS, which address the issue of breastfeeding related to access to information through technology. No time frame was determined, but articles in languages other than English or Portuguese were disregarded. Finally, 5 articles were selected for the synthesis of this integrative review.

Results: Results from different studies showed that the use of technology represents an opportunity to offer support and education to women in the puerperium who could not receive them in the traditional environment, informing them about pregnancy, childbirth, puerperium, infant feeding, and breastfeeding. This becomes possible through social medias such as Facebook, Instagram, YouTube, and email. These networks provide videos, images, folders, and booklets that aim to solve the main doubts about breastfeeding. Questions such as the frequency that the newborn should be breastfed, which should be 8 to 12 times a day for at least 15 to 20 minutes per feeding, which should end spontaneously according to the infant's satiety if suction is correct: with audible swallowing sounds and no tongue noises being heard when the baby should be breastfed for the first time: ideally in the first hour after birth duration of exclusive breastfeeding, which should last at least six months, according to the WHO. In this way, the information contributes to the reduction of early abandonment of breastfeeding, which makes it essential for health professionals to get involved with the use of technology for health education actions, since breastfeeding is a strategy to promote bonding, affection, protection and nutrition for the child and an effective intervention to reduce child morbidity and mortality, malnutrition and obesity indicators.

Conclusion: Technology is not only about new equipment and devices but involves attitudes and behaviors that seek to care for others with dignity. This process, which is based on scientific knowledge, should provide support to nursing women in order to reduce early weaning triggered by lack of information or poor assistance from health professionals.

Keywords: Breastfeeding. Neonatal. Postpartum period. Technology.

1. Universidade Católica de Brasília (UCB)

Technology-assisted communication for Autism Spectrum Disorder

Ana Clara Monte Varandas[1]
Ana Beatriz Caetano Santos de Sá
Ana Clara Moreira Almeida
Beatriz Eler de Lima
Caio Toscano Lessa
Helena Monte Varandas
Pedro Augusto Goncalves dos Santos

Abstract

Introduction: Autism Spectrum Disorder (ASD) is a neurodevelopmental pathology characterized by symptoms such as difficulties with speech, motor skills, attention, repetitive behaviors, and lack of social awareness. Assistive Technology (AT) has become increasingly important in recent years to provide alternatives for communication and improve the social relationship skills of children with ASD. One successful application of AT is Augmentative and Alternative Communication (AAC).

Objectives: The main purpose of this review is to evaluate the role of AAC and technological interventions in the development of social behaviors of children with ASD. Additionally, this review aims to discuss how the most up-to-date devices contribute to complementing cognitive skills.

Methods: On March 10, 2023, a structured literature search was conducted in the PubMed platform, using the keywords 'children', 'self-help devices' and 'autism'. Only meta-analysis, reviews, and systematic reviews published since 2020 were considered. A child age filter (birth-18 years) was used for the search. A total of 8 results were found, and after a content and relevance analysis, 4 of them were used.

Results: AAC is a highly innovative strategy that is extremely helpful for ASD children since it supports them with the ability to establish clearer speech and it works as an instrument for the socialization process. There are two categories of AAC: aided and unaided AAC. The first one includes physical devices that can be low, mid, or high-tech systems, for instance, communication boards with symbols, objects, pictures, apps, and output devices. The second one involves gestures and facial expressions. ATs are nowadays used in the therapeutic management of children with complex communication needs in an effective way. This type of technology is crucial to address intellectual disabilities and raise academic performance. Furthermore, AAC is a mechanism that creates an environment that allows individuals to learn in a more comprehensible and comfortable way, and it prevents anxiety and impacts such as bullying and social rejections that are common in ASD children's routines at school, for example. However, despite the huge variety of benefits that AAC provides, it has financial implications, since AT is not affordable for every ASD child and, therefore, lacks accessibility.

Conclusion: ACC can present multiple strategies for better communication and social interaction and can be useful for ASD children. ACC enhances relationship skills and prevents anxiety and social rejection. Nevertheless, some high-tech devices are not available for everyone, and efforts should be made to decrease costs. More studies are needed to evaluate precisely the effects of this type of technology.

Keywords: Children. Self-help devices. Autism.

1. Universidade Católica de Brasília (UCB)

Telehealth/Telemonitoring in physical, hearing, visual and intellectual rehabilitation in the outpatient care of the Unified Health System in different regions of Brazil

Glaciele Nascimento Xavier[1]

Abstract

Introduction: Telehealth/telemonitoring allows the assistance and monitoring of health parameters and diseases of the patient through communication technologies in physical, hearing, visual and intellectual rehabilitation with lower cost in the different levels of healthcare.

Objective: To describe the number of consultations carried out by telehealth/telemonitoring in physical, hearing, visual and intellectual rehabilitation in the outpatient care of the SUS in the different Brazilian regions in the period from January 2018 to November 2022.

Methods: Information was obtained from telehealth/telemonitoring in physical, hearing, visual and intellectual rehabilitation in the outpatient care of the SUS in the different Brazilian regions from January 2018 to November 2022, using the information available in the SIA/DATASUS? Department of Informatics of the Brazilian National Health System (SUS).

Results: No data were found in the DATASUS Department of Informatics of the Brazilian National Health System (SUS) about telehealth/telemonitoring in physical, hearing, visual and intellectual rehabilitation, from January 2018 to December 2021. Because of this, the analysis period was January 2022 to November 2022. A total of 625 consultations were carried out in hearing rehabilitation, 31 consultations carried out in the north region, 71 consultations in the northeast region, 507 consultations in the southeast region and 16 consultations in the south region. No data were found on attendances in the midwest region. A total of 260 consultations were carried out in visual rehabilitation, 40 consultations carried out in the north region, 02 consultations in the northeast region, 218 consultations in the southeast region. No data were found on consultations in the midwest and South regions. A total of 22,358 consultations were carried out in physical rehabilitation, with 06 consultations carried out in the north region, 17,405 consultations in the northeast region, 4,547 consultations in the southeast region, 216 consultations in the south region and 184 consultations in the midwest region. A total of 12,965 consultations were carried out in intellectual rehabilitation, with 418 consultations carried out in the North region, 2,773 consultations in the northeast region, 9,289 consultations in the southeast region, 460 consultations in the south region and 25 consultations in the Midwest region. No data were found in DATASUS about the values approved to telehealth/telemonitoring in physical, hearing, visual and intellectual rehabilitation, from January 2018 to November 2022.

Conclusion: The information obtained on telehealth/telemonitoring in physical, hearing, visual and intellectual disabilities rehabilitation in the analyzed period demonstrated an opportunity for the increase of these services in the different regions of Brazil. No information was found in all regions of Brazil on carrying out assistance in hearing and visual rehabilitation.

Keywords: Telemonitoring. Rehabilitation. Public health. Telehealth.

1. Hospital da Criança de Brasília (HCB)

Telemedicine in the follow-up of children with rare diseases

Maria Fernanda Araujo Batalha[1]
Verônica de Oliveira Santana
Amanda Einsiedel Ribeiro
Larissa Neris Oliveira de Souza
Liandra Pimentel de Castro Martins
Maria Carolina de Almeida Granjeiro
Alanna Ferreira Alves[2]

Abstract

Introduction: In recent years, telehealth has shown an exponential advance from telemedicine, aiming to provide more economical and faster medical follow-up. Initially, its implementation was centered on adult patients. However, after realizing the optimization of care and the need for medical care for children, telemedicine reached pediatrics and its subspecialties. In pediatric patients with rare diseases, telehealth shows to be promising. Remote patient monitoring alternating teleconsultations with face-to-face appointments and long-term follow-ups with reduced costs and displacement of critically ill patients, are all examples which can be implemented.

Objective: Evaluate pros and cons of telehealth in the follow-up of children with rare diagnoses.

Methods: Bibliographic review of 5 articles in Portuguese and English, published in the BVS, Lilacs, Scielo and PubMed databases, from 2014 to 2021, under the following criteria: text available and recent publication, and the exclusion factors: approaching other age groups and topic tangency. The descriptors used were 'Telemedicine,' 'Child Health' and 'Rare Diseases.'

Results: Tele pediatrics makes it possible to face obstacles in the care of children with rare diseases, such as default of access to specialized professionals, risk of infections and higher expenses for traveling to tertiary centers, due to its asynchronous, synchronous, and remote monitoring operation. Asynchronous consultations allow the communication and forwarding of patient data and remote evaluations, increasing accessibility to specialized services, irrespective of time or place. The synchronous one – especially videoconference – is applied in follow-up routine, medication update, surgical preadmission testing and postoperative pain management and follow-up. Remote patient monitoring through mobile apps and sensory devices allows for update of patient's health conditions, delivering that real-time information to the health professional, enabling an immediate and more precise adjustment of therapy, which decreases illness morbidity and mortality and strengthens doctor-patient relationships, as well as allowing home diseases control. However, there is worry that telehealth will increase existing inequality, considering the heterogeneous access of the population to the internet and cell phones, especially patients in social vulnerability. In addition, the lack of monitoring of the quality of medical practices carried out in this environment, the uncertainty of the physician's ability to correctly diagnose without performing a physical examination in person with precision and accuracy, and the guarantee of privacy and security of the data collected by remote monitoring devices, make up the current problems faced by this type of service. The scarcity of articles addressing the use of telemedicine with the pediatric population with rare diseases is highlighted, and it is crucial to invest in research to prove its benefits or harm.

Conclusion: Telehealth has brought several benefits to the monitoring of children with rare diseases. However, due to the scarcity of public policies and a strong socioeconomic disparity in society, the digital marginalization contributes to the non-use of telemedicine by the pediatric public, demanding measures to change the current scenario. Furthermore, it is essential that health services not only regulate and train professionals to ensure the best applicability of the service in each area, but also to help them adapt to the technology.

Keywords: Telemedicine. Rare diseases. Pediatric.

1. Universidade Católica de Brasília (UCB)
2. Hospital da Criança de Brasília José Alencar (HCB)

Elizabeth G. Vilarino de Castro C.[1]
Juliana F. Lograd Almeida[1]

Abstract

Introduction: The work of the librarian in the area of healthcare is still a recent activity in Brazil, particularly when compared to the reality of the United States of America or European countries, where these information professionals, since the beginning of the 1970's, have exercised this function of assisting in the search for information to support diagnoses and prognoses, as well as research and studies. Librarians working in libraries at medical schools or hospitals, such as the Library at the Hospital da Criança de Brasília José Alencar (HCB), work to efficiently provide clinical teams, researchers, and students with information on health, either with means of training for the use of specialized databases, or research and/or bibliographical surveys.

Objective: To describe the role of the librarian working in the healthcare area and their contributions to decision-making.

Methodology: A comparative study was carried out based on a bibliographical review, in Portuguese, in the ScIELO, CAFE-Capes and Brapci databases, with no time limitation, based on the keywords: "librarianship and health", "librarian doctor" and "librarian and evidence-based health", aiming to compare the main services developed by this professional in health organizations with those provided by the HCB Library.

Results: 308 works published between 1972 and 2022 were found in the bibliographic databases. After excluding duplicate works, 50 articles remained. After reading and applying inclusion and exclusion criteria, 6 articles made up our analysis.

Conclusion: From the review, it was found that the services of bibliographical survey and training of users for the use of databases are the ones that stand out the most. The HCB Library is not different. In monitoring carried out between the months of April 2021 and September 2022, a total of 37 requests for bibliographic surveys were recorded, and a total volume of 15 user-training events produced an amount of 170 trained people. The analysis of these results, when compared to the total volume of health professionals at HCB, points out that these numbers could be more expressive. Among the factors that contributed to these numbers not being more expressive, the lack of knowledge on the part of these users of the services offered by the Library was identified as the main cause. Future actions to publicize these services is an essential measure to reach professionals who are part of the Hospital clinical and research teams, considering that the librarian's role can help both in decision-making regarding diagnosis and treatment, as well as in research and studies, with the provision of relevant and necessary information for the exercise of medical-hospital activity and research.

Keywords: Librarian – work in health. Decision making. Health. Information management. Librarian.

1. Hospital da Criança de Brasília José Alencar (HCB)

The costs of importing dactinomycin for a high-complexity pediatric service

Adriele Alves Santos[1]
Anna Beatriz Gomes da Silva[1]
Igor Alves Mota de Lima[1]
Rafael de Souza Martinez[1]
Kalina Kelly Alves Ribeiro[1]
Leandro Pereira Bias Machado[1]

Abstract

Introduction: Dactinomycin is a medication that belongs to the group of antitumor antibiotics and is indicated for the treatment of some types of pediatric cancer without therapeutic alternatives of the same efficacy and safety in the national scenario, such as Wilms Tumor and Sarcomas. Until 2018, the acquisition of dactinomycin to meet national needs was done in a centralized way by the Ministry of Health (MS), a fact that was interrupted by the publication of circular no. 08/2018 of the general coordination of specialized care, which transferred the acquisition to units of high complexity in oncology. In the absence of registration in the country, importation becomes the only regulated form for the acquisition of the medication.

Objective: Identify the costs of the importation process of dactinomycin by individuals, for the treatment of the onco-hematology service in a high complexity pediatric hospital in the Federal District, from September 2020 to December 2022.

Method: This is a descriptive study related to the importation process of dactinomycin, evaluating costs and quantities through the survey of invoices issued between September 2020 and December 2022. For comparison purposes, the unit value of the dactinomycin vial paid by the Ministry of Health in the first semester of 2018 was surveyed. The consultation was carried out through the institutional system of the hospital under study. From then on, the data collected were transferred to quantitative analysis in the Excel® program.

Results: During the period defined by the study, 25 importation processes were carried out by individuals, corresponding to 549 vials of dactinomycin with an average of 22 vials per process. The total expenditure with importation was R$561,974.97. When stratified, R$532,757.26 (94.8%) corresponded to the value of the medication, R$23,113.61 (4.1%) to international freight, and R$6,104.10 (1.1%) to the value of the service. The average unit value of the medication was R$989.24, which compared to the previous study carried out in the same institution between May 2019 and August 2020, had an increase of 11%, since the average price recorded previously was R$890.44. The last units of dactinomycin received in the hospital in study acquired by the Ministry of Health had a unit price of R$182.53, that is, 81% lower than the current price.

Conclusion: The present study demonstrated the increase in the unit price of dactinomycin in the mode of importation by patient when compared to the previous study carried out between 2019-2020. as the study identified a difference of around 81% between the values paid by the institution studied and the Ministry of Health in 2018 in the acquisition of the same product. The purchase by individual is currently the mode practiced in the institution studied, and the high price of the medication may limit access to the treatment of patients with pediatric tumors.

Keywords: Dactinomycin. Importation of products. Oncology service. Hospital.

1. Hospital da Criança de Brasília José Alencar (HCB)

Giovana Cristina dos Santos Freitas[1]
Letícia Rocha Moreira
Mariana Quirino de Oliveira

Abstract

Introduction: Children with chronic, multisystemic health conditions and with significant functional limitations may require palliative care. In this context, it is important to evaluate telemedicine as a tool to assist in the home monitoring of these children, avoiding unnecessary hospital visits and possible associated complications.

Objective: The objective of this study was to highlight the role of telemedicine in the home management of children who need palliative care.

Methods: This is a narrative and descriptive literature review, with information from the MEDLINE/PubMed database. The research was performed using the Medical Subject Headings (MeSH) 'Telemedicine,' 'Child' and 'Palliative Care' associated by the Boolean Operator "AND". Twenty-seven articles were found between 2018 and 2023. Inclusion criteria were: (1) original articles and/or literature reviews, (2) emphasis on the role of telemedicine in supporting the follow-up of pediatric patients with palliative care needs (3) in English or Portuguese. Exclusion criteria were articles focused on (1) adult health and (2) use of telemedicine for other purposes. After careful reading of the abstracts and application of the inclusion and exclusion criteria, seven articles were selected for further analysis.

Results: Telemedicine may be a promising strategy to increase access to palliative care for children with serious illnesses due to its ease of use and potential to save time and money, both for the patient and healthcare professional. In addition, it was observed that telemedicine can be a useful tool in decreasing the burden on caregivers, with most caregivers reporting that its use was safer and more convenient than face-to-face care, without compromising the quality of care or satisfaction with the consultation. This resource also proves beneficial in situations where the child and his family live in rural areas, where access to a health service that offers palliative care is more challenging. However, it was observed that the passive exposure of information alone is not enough, and the use of more interactive methods, such as audiovisual resources and text messages, is more beneficial. Finally, it is essential to adapt this tool to the reality of each patient, considering their particularities and needs, related to their disease, symptoms, and context, as well as evaluating how comfortable the family feels in implementing this tool in their daily lives.

Conclusion: Telemedicine has the potential to assist in the management of symptoms of patients in need of palliative care. However, there is still a need for further research to evaluate the effectiveness of telehealth in improving the quality of life of these patients and its ethical implications, as well as the need for the individualization of these technologies, so that it can optimize patient care.

Keywords: Telemedicine. Palliative Care. Child.

1. Universidade de Brasília (UnB)

The effectiveness of the use of ultrasonography in blunt trauma in children: a literature review

Manuella Munitor Cardoso Cunha[1]
Bianca de Carvalho Nóbrega
Jacqueline Guerra Corradi Passos
João Pedro França Meira
Levi Durães Batista da Silva
Marcus Vinicius Albino Amaral
Tiago Medeiros Nobre

Abstract

Introduction: Most pediatric abdominal injuries result from blunt trauma. The diagnosis of these injuries is usually done with computerized tomography (CT), since the efficacy of Focused Assessment with Sonography for Trauma (FAST) has been the subject of debate instigated by reports of low sensitivity and high false negative rates. However, FAST offers advantages like demanding less time, allowing reevaluation throughout resuscitation, and avoiding ionizing radiation, which is important because children are at higher risk for malignancy induced by ionizing radiation compared to adult patients.

Objective: This review aims to investigate the current efficacy of ultrasonography in identifying injuries caused by blunt abdominal trauma in pediatric patients.

Methods: For this literature review, a search strategy was carried out on the databases PubMed and Lilacs, using articles published from 2018 to 2022. The following Mesh terms were used on the search: ultrasonography, focused assessment with sonography for trauma, and child. It resulted in the finding of 15 articles in PubMed and 16 in Lilacs, but 14 of these were the same. Only studies published in English and Portuguese were considered. Studies that did not assess ultrasound in pediatric emergency, were experimental, referred to adults, were not relevant to the objective, and the ones in which it was not possible to analyze the full text were ruled out. At the end, 11 articles were selected.

Results: The current literature base about FAST in children with blunt trauma is inconsistent and leads to variable practice patterns. On this review, these results were found: since it is a user dependent technique, professionals should be more trained to perform and interpret FAST on children, since these have specific characteristics, such as physiological free fluid and smaller body habitus. FAST is not a replacement for CT scans but instead, if performed correctly, may be a tool within a diagnostic strategy for identifying the need for advanced imaging, resource utilization, or acute interventions. The presence of negative results in FAST and in repeated FAST combined with the presence of abdominal tenderness suggests low chance of intra-abdominal injury in blunt trauma, which can reduce the need for CT scans. Fractures of the pelvis or spine and severe head injuries can be associated to a false-negative FAST result, so in this case it is advised to proceed with a more detailed investigation. FAST may not be completely effective as a triage tool to diagnose intra-abdominal injuries on children, but some characteristics can be useful to suspect a positive result: physiologic free fluid (FF) of less than 1 ml within the pelvis is a common finding in the pediatric population, pointing a low probability of intra-abdominal injury, but the presence of FF outside the pelvis indicates intra-abdominal injury. Unstable vital signs and higher gravity injury scores are associated with a positive result in FAST.

Conclusion: The use of FAST alone is not enough to rule out intra-abdominal injuries from blunt trauma. However, if combined with physical examinations and reFAST, it can be effective to reduce the need of CT on patients with negative results.

Keywords: Ultrasonography. Focused Assessment with Sonography for Trauma. Child. Emergency. Abdominal Injuries.

1. Escola Superior de Ciências da Saúde (ESCS)

The impact of built environment on patients with sensory processing disorder in a tertiary pediatric hospital: identifying triggers of discomfort

Daniela A. Guterres Soares[1]

Abstract

Introduction: The human body perceives the built environment through its senses, and the interpretation of these senses affects our mental and physical well-being. Previous experiences and their sensory relationship with space are linked to emotions and memory. Considering the differences in understanding the environment in neurotypical and atypical individuals and the importance of the physical environment in promoting comfort, this study aims to identify triggers of discomfort in patients with Sensory Processing Disorder (SPD) that could potentially be alleviated through modifications to space.

Objective: The aim of this study is to investigate the sources of discomfort experienced by children with atypical sensory processing during hospital visits or stays. The ultimate goal is to propose architectural design guidelines tailored to the specific needs of this patient population in future research endeavors. By identifying the factors that trigger discomfort in these patients, this study seeks to contribute to the development of architectural solutions that promote their well-being and comfort.

Methods: This descriptive exploratory qualitative study is using a theoretical and phenomenological approach through a semi-structured survey that contains questions concerning specific situations experienced by the interviewees, encouraging them to speak freely about the topic. The interviews are being conducted in person, and the answers are being cataloged and qualitatively analyzed. Patients diagnosed with clinical conditions related to Sensory Processing Disorder, who were over 2 years of age, met the inclusion criteria. However, patients under 2 years of age or on their first hospital visit were excluded from the study. This research project was approved by the Ethics Committee.

Results: So far, 22 interviews with children aged 2 to 14 years old have been analyzed. These children were patients of different specialties at the Hospital da Criança de Brasília, with a predominance of neurology (27% n=6), oncology (27% n=6), and gastroenterology (22% n=5). The three leading sources of agitation crises were hearing – impulsive and continuous noises (73% n=16), tactile – touch (73% n=16), and vision – perception of order (68% n=15). Only 27% (n=6) of the patients classified noise as not being a source of disturbance, whereas the others reported it as the most sensitive sense. Therefore, it was possible to determine the essential elements for the precepts of architectural design criteria for spatial alterations, and the necessity to adapt the environment.

Conclusion: Based on the identification of the patient's profile and their relationship with their surroundings, it was possible to identify problems that should be considered in creating guidelines for new spatial interventions in future designs and adaptations. The following recommendations should be taken into account: providing a designated area for patients to wait for consultations, in-patient rooms with acoustic treatment, compartmentalizing open areas to ensure the child's privacy and sense of safety, implementing visual hygiene techniques to promote order and routine, and others. Such spatial adjustments are expected to result in greater comfort for the patient, primary caregivers, and professionals who actively interact with the child.

Keywords: Sensory disorder. Hospital design and construction. Evidence-based facility. Design. Built Environment. User-centered design.

1. Hospital da Criança de Brasília José Alencar (HCB)

The importance of providing early palliative care in pediatric cancer patients

Amanda Cristina da Cunha Arruda
Amanda Saraty Teixeira
Ana Luísa Chaves Rocha
Isabella Torres Furbino Malafaia
Guilherme Martins Tolini
Victoria Servidoni da Silva

Abstract

Introduction: According to the World Health Organization, pediatric palliative care is defined as active and total care (body, mind, and spirit) provided to the child, as well as support offered to the family. It can be used early in the context of oncological diseases, even when the child is expected to improve from the condition, being a way to humanize the patient's treatment and avoid unnecessary suffering. Palliative care respects the individual choices and needs of each family, being an extremely important implementation.

Objective: The main objective of the present work is to highlight the advantages of implementing early palliative care in pediatric oncology.

Methods: This is a systematic literature review with bibliography selected from Google Scholar databases with 'palliative care in pediatric oncology' as a keyword. The eligible articles were the ones in Portuguese and published in the last 10 years. Five articles were used to make this review.

Results: The need for palliative care for children is similar to that for adults and, although rarer, there are several plausible situations of pediatric palliation, the main one being the occurrence of oncological diseases. According to the Global Cancer Observatory, malignant neoplasms affect about 29,000 children per year and are the second leading cause of death under 14 years of age. With that said, palliative care emerges as a strategy that provides better control of symptoms and a better quality of life for children and their families, and should be instituted at the time of diagnosis, even when there is curative treatment. Palliative treatment in pediatric oncology is essentially focused on pain control. Research shows that non-pharmacological treatments (such as music therapy, acupuncture, games) combined with pharmacological measures can increase the success of pain treatment, since non-pharmacological measures help to relieve the child's tension to perform painful and possibly traumatic procedures, providing a humanized care. In addition, palliative care, especially in pediatric oncology cases, has an important focus on family-oriented care, having in mind that the family are going through a great moment of uncertainty. And, in cases of child death, this care for the family extends into the family mourning. It is clear, then, that the late institution of palliative care is directly related to the suffering of the child and the family, especially in the last days of life.

Conclusion: Pediatric oncological diseases are included among the main situations in which the early institution of pediatric palliation is necessary. Pediatric palliative measures aim at principles of pain treatment of the child, through both pharmacological measures and non-pharmacological ones. Palliative care also addresses support for family members during the child's treatment and during the period of mourning. Therefore, early institution of palliative treatment in pediatric cancer patients is fundamental for the total and humane care provided to the child and his/her family to be established.

Keywords: Palliative Care. Pediatrics. Medical oncology.

The importance of the use of tele phonoaudiology in monitoring the care of children with cleft palate – literature review

Micaela de Jesus Lisboa[1]
Andressa Kelly de Araújo Vasco Moreschi
Beatriz de Souza Feitoza
Izabelly Aparecida Nunes Barros
Karen de Souza David
Michelly Felix Chavier
Ana Luiza Vieira Benito

Abstract

Introduction: According to the care and follow-up needs of children with cleft palate and their parents/guardians, especially soon after leaving the maternity ward and throughout their development, it is possible to mention telemonitoring in tele phonoaudiology as a means of remote care, even with the difficulties of evaluations and application of techniques, depending on age and degree of severity (UBERTI et al., 2022). Therefore, it is extremely important to find out in the scientific literature about the need for this technological tool to guide and monitor children with cleft palate and the parents/guardians of these patients.

Objective: To present how telemonitoring, within speech therapy, can facilitate the follow-up of children with cleft palate and the orientation of parents/guardians of patients, and to identify the main technological means that already exist in the orientation of cleft palate.

Methodology: This work is a literature review, using the following inclusion criteria: articles published from 2010 to 2022, from the first page of the databases, about newborns and children with cleft palate, after maternity discharge, who needed speech therapy monitoring during their development, especially after surgery. The search was carried out in Portuguese and English language databases with the descriptors (DECS): 'cleft palate', 'speech therapy' and 'telemonitoring' and its correlates in English language (MESH): cleft palate and speech therapy available in full in the following databases Periódico Capes, Scielo, PubMed, Cochrane and Lilacs, as well as in Laws, books and websites that involve the theme, such as the TabNet of the Ministry of Health that is part of the databases of the Unified Health System. In order to collect information for our article, we analyzed review articles reading and analyzing quantitative data regarding the use of tele phonoaudiology in the country during the pandemic. Each author was responsible for collecting information from a given database and describing it.

Results: A total of 116 articles were identified and 11 selected: Periódico Capes (1 article), Scielo (4 articles), PubMed (1 article), Cochrane (3 articles) and Lilacs (2 articles). It was observed through the literature review that the tele phonoaudiology can be performed online even with difficulties to evaluate and apply the phonoaudiological techniques, because they depend on the child's age and the severity degree of the pathology (UBERTI et al., 2022). There are several forms of care in tele phonoaudiology, among them telemonitoring that through ICTs (Information and Communication Technologies), the speech therapist can monitor the results of the sessions on a weekly basis and also provide information to parents/guardians of children with cleft palate (CFFa, Resolution No. 580, 2020).

Conclusion: Bearing in mind the need to expand studies, mainly quantitative and qualitative field research with Brazilian speech therapists, as well as the methodological strength of research in multiple areas of speech therapy, such as the rehabilitation of patients with cleft palate, there is already scientific evidence supporting the use of ICTs in speech therapy.

Keywords: Cleft palate. Speech therapy. Telemonitoring.

1. Universidade de Brasília (UnB)

The participation and importance of nurses in clinical research

Paulo Ricardo Ferreira do Nascimento[1]
Analice Sofiste Lima de Freitas
Letícia Cristina Alves do Nascimento

Abstract

Introduction: In the field of nursing, the role of the nurse as a researcher is not discussed and known, as it is a different universe from conventional care. Despite this lack of awareness, the researcher nurse is of paramount importance for promoting wellness and longevity of the patient included in research, in all phases of treatment.

Objective: To describe and understand, according to the literature, the actions, and challenges for nurses in clinical health research.

Method: Searches were carried out in the Scientific Electronic Library Online (SciELO), using the following keywords: nursing, clinical trial, clinical protocols, in Portuguese and English, in selected articles published in the last 5 years. Through the analysis and bibliographic review, it is noted that the presence of qualified and well-trained nurses is established by the international standards of Good Clinical Practice. In addition to a suitable place for conducting clinical research, with these conditions met, it is possible to meet the needs of clinical protocols, where the nurse's participation ranges from assisting the research subject, such as collecting material for laboratory tests planning, organizing and executing the protocols involved, such as the nurse coordinator, responsible for study logistics, conducting all procedures at the research center. In this way, the researcher has several attributions during the conduct of a study protocol, thus needing to be trained in regulatory matters, requirements of the ethics committee, language of the protocols, always prioritizing the clarity of the data obtained in the study and the safety of the participants.

Result: Three articles were analyzed and selected, one of which was used for the basis of this work. The analyzed article claims that research is fundamental and indispensable to answer questions related to promotion, prevention, treatment, and counseling in health, requiring the performance of trained professionals to carry out the various tasks and clinical protocols, the presence of nursing in clinical research has been increasingly present and explored. The main challenges are found in the elaboration of planning based on the protocol, in the training of professionals in the bureaucratic regulatory part for approval of the research, in addition to the fact that the theme is not in their wide domain and its functions are poorly defined, thus requiring discussion in this regard.

Conclusion: It is concluded that nursing in clinical research is still under enhancement and needs to be better delimited in its functions and more disseminated to professionals in the area. The insertion of nurses in research, although requested, is still new and requires improvement and training, but even with all these challenges, the role of nursing in clinical research is of paramount importance for the performance and follow up of the research.

Keywords: Clinical research in nursing. Nursing education. Analysis. Clinical research protocol.

1. Centro Universitário do Distrito Federal (UDF)

Problems with the lack of completeness of data in nursing notes and evolutions

Analice Sofiste Lima De Freitas[1]
Letícia Cristina Alves do Nascimento
Paulo Ricardo Ferreira do Nascimento

Abstract

Introduction: Renowned nurse Florence Nightingale reported in her book, Notes on Nursing, that "it was essential that the facts observed by the nurse were reported to the doctor accurately and correctly," as she mentioned in the medical records was a way of reporting information to doctors. Nowadays, the patient's medical record is a document of fundamental importance for storing all clinical data of the sick person, directed not only at the institution's physician. Nursing notes are one of the major references for obtaining data from a patient in the midst of multidisciplinary treatment, because the nurse is in continuous contact with the patient. Making complete and clear evolutions also contributes to better patient care, has important data for the continuation of care by different team members and directly influences the way they can accomplish it. In addition, the medical record is a way to ensure both the safety of the professional and of those who are receiving the treatment.

Objectives: To raise the problems generated by lack of information in nursing notes and evolutions, according to the literature, and how it affects the dependents of this information and discontinues patient care by other teams of the institution, including the clinical research area.

Methods: This is a literature review on The Problems in The Lack of Completeness of Data in Nursing Notes and Evolutions. Searches were carried out in full, between 2005 and 2019, using the key words: nursing records, electronic medical records and clinical data.

Results and Discussion: Four types of research were investigated and chosen – articles, completion papers and case studies. The analyzed studies present the medical records as a way to facilitate both the work of the professional and the patient's experience within a hospital environment, giving suggestions for improvements and concepts on such a subject. It is seen that it is very common to find errors in data, which causes difficulties in several areas such as the audit of data and funds.

Conclusion: It was noticed that the problems within the medical records are extremely complex and enigmatic, where there are valuable solutions, such as electronic medical records being a great key to exterminate such situations. It represents a great responsibility for the professional when performing such a role, which requires seriousness and deep respect for the patient.

Keywords: Nursing evolutions. Clinical Data. Medical records. Nursing notes.

1. Hospital da Criança de Brasília José Alencar (HCB)

The prognostic significance of CRLF2 expression in pediatric acute lymphoblastic leukemia

Aldemiro Sousa Jorge Junior[1]
Ricardo Camargo[1]
Larissa Lemos Mendanha Cavalcante[1]
Marina da Costa Ribeiro[1]
Agenor de Castro Moreira dos Santos Júnior[1]

Abstract

Introduction: Acute lymphoblastic leukemia (ALL) is a heterogeneous group of neoplastic diseases, and in pediatric patients, it is the most common type of leukemia. Type B (B-ALL) is a subset of acute lymphoid leukemias comprising 75% of ALL cases. There is a variety of chromosomal alterations and/or rearrangements implicated in B-ALL. Dysregulation of the expression of cytokine receptor-like factor 2 (CRLF2) is observed in 5-15% of patients with B-ALL and occurs mainly through reciprocal translocation with immunoglobulin heavy chain (IGH), deletion in the PAR1 region of X and Y chromosomes, CRLF2 mutations, as well as mutations of pathways involving CRLF2. The literature associates the overexpression of CRLF2 with an intermediate prognostic factor. The prognostic significance of CRLF2 expression at diagnosis in pediatric patients with B-ALL needs to be clarified.

Objective: To analyze the effects of CRLF2 gene alterations in pediatric patients with B-cell acute lymphoblastic leukemia.

Methodology: In this study, 146 patients with B-ALL treated at the pediatric oncology and hematology service at the Children's Hospital of Brasilia were analyzed for CRLF2 overexpression and treatment response. The presence of CRLF2 alterations was analyzed by RT-PCR and MLPA, and CRLF2 expression was determined by RT-qPCR.

Results: Out of 146 analyzed samples, 75 showed alterations in the CRLF2 gene. Of these, 60 had duplicated X chromosome, with 3 showing overexpression. Four had duplications of CRLF2 and fusion with P2RY8-CRLF2 genes, all with overexpression of CRLF2. Four samples did not show alteration in the copy number of CRLF2, but had P2RY8-CRLF2 fusion, all with overexpression of CRLF2. Six patients had overexpression of CRLF2 but had normal karyotype and no alteration in CRLF2. Two patients with P2RY8-CRLF2 fusion had disease relapse, and one progressed to death. Two patients without detection of alteration in CRLF2, but with overexpression, had unfavorable outcome, one had relapse one year after the beginning of treatment, and the other did not survive treatment. One patient with normal karyotype and fusion of P2RY8-CRLF2 genes died during treatment. The remaining analyzed patients are in remission.

Conclusion: Based on the analyzed data, it is possible to conclude that alterations associated with the CRLF2 gene do not have a negative prognostic effect for patients who do not present gene overexpression. However, patients with CRLF2 overexpression, especially those with the P2RY8-CRLF2 gene fusion, may be considered intermediate risk. It is important to note that CRLF2 duplication does not necessarily result in gene overexpression, but fusion with P2RY8 can lead to a significant increase in its expression. Further in-depth analyses of the factors involved in overexpression are necessary to fully understand the associated intracellular events and their effects on leukemogenesis.

Keywords: CRLF2. Overexpression. Leukemia. Children.

1. Hospital da Criança de Brasília José Alencar

The role of home care and strategies in the care of children during the pandemic

Felipe Gabriel Barbosa de Oliveira II[1]

Abstract

Introduction: Home healthcare is a form of medical care for patients in specific circumstances. In pediatrics, children with complex chronic conditions, with or without technological dependence, requiring physiotherapeutic or pharmacological support and having mobility difficulties are eligible for home care. These children are considered a high-risk group for COVID-19 health deterioration, making it necessary to establish strategies to ensure monitoring and maintenance of clinical stability at home during the pandemic.

Objective: This scientific summary aims to highlight the importance of home healthcare in the health system, as well as the main strategies developed to ensure safe patient monitoring during the COVID-19 pandemic.

Methods: It was based on recent literature on child home care during COVID, from the SciELO and PubMed databases. With the descriptors: 'home nursing,' 'home care services,' 'COVID-19', 'pediatric assistants', and inclusion criteria for publications from the beginning of the pandemic until the present date, between 2019 and 2023, in Portuguese, English, and Spanish, and exclusion for those that did not address the theme.

Results: The COVID-19 pandemic increased the demand for beds to treat complications from SARS-CoV-2, resulting in a greater need to release patients from the hospital environment, especially those with prolonged hospitalization, transferring them to home care. To facilitate care in situations where the home care team's presence is not possible, teleconsultation is a distance tool with the aid of technology. During the COVID-19 pandemic, home healthcare played a crucial role in caring for children with complex chronic conditions. The pandemic increased the demand for hospital beds and, consequently, the need to transfer patients to home care, where they can receive care closer to their families and with less risk of contamination. However, the pandemic also brought significant challenges to the home care team, which needed to adjust its practices to ensure the safety of patients, teams, and families.

Conclusion: Standardization of Personal Protective Equipment (PPE) use and adapted home visits were some of the strategies used by the multidisciplinary home care team to ensure care continuity during the pandemic. Additionally, teleconsultation has proven to be a valuable tool to complement care when physical presence was not possible. It is important to note that children with complex chronic conditions are among the most vulnerable groups at risk of COVID-19 complications. Therefore, it is essential to establish safety measures to prevent virus transmission and ensure that these children receive safe and quality care in their own homes. Home healthcare plays a strategic role in facing the pandemic and ensuring continuous care for these patients, contributing to the reduction in demand for hospital beds and to the maintenance of the health and quality of life of children and their families.

Keywords: Home nursing. Home care services. COVID-19. Pediatric assistants.

1. Universidade de Brasília (UnB)

The role of the nurse in promoting exclusive breastfeeding to preterm newborns

Thaís Moura de Ataides
Taísa de Paula Paiva Freitas

Abstracts

Introduction: Breast milk is the main source of food for children, especially those younger than six months. Exclusive breastfeeding is a diet consisting only of breast milk without the intake of other liquids, except medicines. Prematurity comprises the birth of a baby at a gestational age of less than 37 weeks. Increasing exclusive breastfeeding is a goal to be achieved in Brazil, triggered by the commitment established internally and externally about the improvement of healthcare provided to pregnant women, postpartum women, and newborns, aiming at reducing maternal and child morbidity and mortality, besides the countless benefits.

Objective: To identify the role of nurses in the promotion of exclusive breastfeeding in preterm infants.

Methodology: This is an integrative literature review, where the search was conducted in the BVS and PubMed databases using the following descriptors: breast feeding, infant, premature and nursing care, and SciELO using the following descriptors: breast feeding infant, premature, crossing them, and using the Boolean connector AND. The search in the databases was conducted in March 2022, and the inclusion criteria used in the study were as follows: available in full, complete citation in Portuguese, English, and Spanish, published between 2012 and March 2022. The bibliographic survey, carried out by crossing the descriptors in the database, identified 211 articles. Then, the title and abstract of these articles were read, and of these, 58 were pre-selected for reading in full. After reading in full, 46 articles that did not meet the inclusion criteria proposed by the study were excluded. Thus, the sample of this integrative review was composed of 12 articles.

Results: The articles included in this review sought to evaluate actions developed by the nurse to promote breastfeeding for premature newborns, promoting actions to assist breastfeeding. Throughout the research, the following actions favoring breastfeeding in premature newborns were observed: milking during hospitalization orientation about the correct grip and proper positioning of the baby during breastfeeding, the importance of the Human Milk Bank, the Kangaroo Method, the support network, and orientation about the protective rights to the practice of Breastfeeding.

Final considerations: Considering the findings of this study, it was verified that the theoretical and scientific knowledge of nurses about the promotion of breastfeeding for pre-term newborns is indispensable, since the greater the woman's learning about breastfeeding, the greater are the chances of establishing exclusive breastfeeding. There is a need to highlight the importance of the nursing team's actions in strengthening the relationship between the team and the family, aiming at the promotion and adherence of evidence-based practices that are associated with greater breastfeeding effectiveness, in addition to the promotion of actions that help in the breastfeeding process.

Keywords: Breast feeding. Infant. Premature. Nursing care.

The role of university extension as political support in the context of Sickle Cell Disease

Nely Fernandes Xavier Correia[1]
Luiza Gabriela Noronha Santiago
Ana Luisa Ines Silva
Charlene Regina da Cruz
Larissa Mirelly Mendes Carvalho
Lorenza Carvalho Caser
Elaine Cristina Rodrigues Gesteira

Abstract

Introduction: Sickle Cell Disease (SCD) encompasses a set of hereditary hemoglobinopathies, the most complex and severe being sickle cell anemia, due to its homozygous form. The origin of the disease dates back to the African continent, which is why its manifestation is associated with the African population and its descendants. Thus, extension and research programs become a tool to welcome and politicize family groups with the objective of providing self-care, health education and structuring a municipal support network.

Objective: To describe the experience of a non-profit association with parents of children with sickle cell disease, as a support tool for coordinating the care of families with SCD.

Method: Descriptive study, of the type of experience report, experienced by nursing and medicine student participants of the Extension Program Educar Falciforme (EF), linked to the Federal University of São João del Rei – UFSJ, Centro-Oeste Campus, in Brazil.

Results: In mid-2021, the EF group reorganized itself to set up a non-profit association for families with SCD. The entire bureaucratic, legal, and administrative process for the setting up was established by the Program. However, the continuity of the association was reliant upon the families that took part in it, to allow family members to share experiences and develop bonds, providing an exchange of knowledge, difficulties and anxieties, ensuring more commitment to coping with the situation, in addition to contributing to knowledge and assisting families towards correct treatments, providing information about SCD and the rights they have. However, with the advent of the COVID-19 pandemic, actions are being performed in remote and synchronous mode, with monthly meetings and individual orientations for each family nucleus. In this context, there are some aspects hindering the interaction of these family members with the Association, since some are having difficulty accessing the Internet, as well as interrupting the usual activities to take part in the meetings. Moreover, this form of communication brings with it a deficit in establishing bonds between the students and the individuals participating in the Association, especially in regard to recognizing family needs evidenced with notoriety in home visits, with loss of family involvement. However, as a positive factor, families spontaneously report the feeling of welcoming, thanking the listening space and support, reinforcing the positive impact of the meetings regarding the whole care of these children.

Conclusion: It is notable that the establishment of rights and assistance of people with SCD have ethical, political, economic, social, human, and medical implications that should be considered in all its possibilities. Thus, through the Educar Falciforme Program and the family members association, it is expected that people with SCD get full access to the totality of their rights, especially children with this condition, who are the focus of this association, and as a consequence better care promotion and quality of life.

Keywords: Sickle cell anemia. University extension. Health education Family.

1. Universidade Federal de São João del Rei (UFSJ)

The use of artificial intelligence (AI) for radiological diagnosis in pediatric trauma: a literature review

Jacqueline Guerra Corradi Passos[1]
Daniele Eloise Duda
Helena Guedes Oliveira
Aline Feitosa Pessoa
Luíza Rocha de Souza
Tiago Medeiros Nobre
João Pedro Zavattiero Tognolo

Abstract

Introduction: Traumatic injuries in orthopedics and traumatology, constitute the most important cause of death in children over one year old and their effective diagnosis assists in a favorable prognosis for the pediatric patient. Although the use of Artificial Intelligence (AI) in detecting bone fractures has been growing rapidly in recent years, this method is still prevalent for use in adults, lacking reports that focus on the pediatric population.

Objective: This review aims to clarify the effectiveness of the use of AI for detection and rapid aid in the diagnosis of various bone fractures in the pediatric public, evidenced by radiography, in hospitals and in emergency services, since early diagnosis plays a primary role in the patient's prognosis, for early and correct treatment.

Methods: The selection of articles was carried out using the PubMed database, in which the Mesh Terms 'artificial intelligence', 'child', 'pediatric', 'radiography' and 'injuries' were used, finding 24 articles. After excluding studies based on other imaging tests and those not found in their entirety, nine papers were used to write this literature review.

Results: It's noteworthy that many countries have scarce specialized professionals in pediatric radiology, especially in emergency services. In this fashion, the use of AI is an important tool to help both specialists and other health professionals in the interpretation of the radiographic technique. High sensitivity and specificity of the performed tests was observed, especially in areas of the elbow, hands, and feet. It was also useful to perform difficult diagnoses in cases of overlapping bones, anatomical variations, different moments of ossification and local angulation of the image, especially for residents or less experienced physicians. To carry out the research, it was observed that its work is complementary to the human interpretation of the tests, unlike other current AI, which perform the diagnosis from an uploaded database.

Conclusion: Accurate diagnosis and effective treatment can reduce children's pain, shorten healing time, and prevent malunion and neurovascular complications from bone trauma. Therefore, the use of AI, for both medical specialists and pediatricians, as well as other health professionals in the emergency area, has a positive character as an aid in the speed and accuracy of diagnoses. However, further improvements and studies are necessary for the use of this resource to be more embracing of the pediatric public.

Keywords: Artificial intelligence. Child. Pediatric. Radiography. Wounds and injuries**.**

1. Escola Superior de Ciências da Saúde (ESCS)

The use of cannabidiol for the therapeutics of epilepsy in children and adolescents

Ana Clara Mariano Rodrigues[1]

Abstract

Introduction: Epilepsy is a condition usually diagnosed in childhood, characterized by a persistent brain disorder generating transitory discharges in hyperexcitable neurons. These discharges generate epileptic seizures that, if manifested excessively and repetitively, tend to cause permanent brain damage, learning deficits and behavioral disorders. Tetrahydrocannabinol (THC) and cannabidiol (CBD), compounds from Cannabis sativa, act on the endocannabinoid system to reduce brain activity by the influx of calcium. Henceforth, the use of this drug in epileptic children is being investigated for the control of refractory seizures, aiming at the quality of life of these patients.

Objectives: To correlate, through scientific literature, the use of Cannabis sativa compounds in treatment of convulsive seizures in children and adolescents with refractory epilepsy in the use of conventional drugs.

Methodology: Literature review using the online databases Google Scholar and Scientific Electronic Library Online (SciELO), in which systemic searches were made from the descriptors 'epilepsy,' 'cannabis sativa', 'cannabidiol', 'refractory epilepsy'. The research considered articles written in English and Portuguese, published between 2017 and 2023 that addressed the effects of cannabinoids in relation to the clinic of individuals affected with epilepsy refractory to treatment. After analysis of 8 articles, 4 were excluded for not relating the effectiveness of this therapy in the treatment of epileptic seizures.

Results: The use of cannabidiol (CBD) was considered effective in the treatment of epilepsy in children and adolescents with refractory frames, characterized by the permanence of crises even under use of two or more drugs to contain them. Studies indicated that CBD showed good results in most patients, due to its therapeutic character, without causing any psychoactive sequelae. Also in this context, some cases with complete remission of the disease were reported (SOUSA, et al, 2020, p. 7). In addition, it is described that CBD used with a small percentage of tetrahydrocannabiol (9-THC) or Clobazam® can potentiate its effects. However, some negative effects were noted, such as drowsiness, fatigue, and changes in appetite. The mechanisms of action of this drug involve the endocannabinoid system, which allows the coordination of central functions in the body. In this view, CBD may have an influence on neurotransmitter discharges in presynaptic and postsynaptic neurons by activating CB1 receptors, which are expressed predominantly in presynaptic terminals of GABAergic and glutamatergic neurons. Despite the lack of studies indicating the safety of CBD use in children and adolescents, cannabidiol treatment showed a very significant anticonvulsant effect in patients with epilepsy.

Conclusions: In this sense, it has been noted that the use of THC and CBD is promising from studies that show its effectiveness in cases of drug-resistant epilepsy in children and adolescents. However, research is still limited and there are not enough data (dosage, resistance, side effects and others) to prescribe this compound on an outpatient basis. In this way, more studies are needed to deepen this theme and establish a safe and alternative therapeutic plan for children and adolescents living with epilepsy, as a means of improving the quality of life of these patients.

Keywords: Epilepsy. Cannabis sativa. Cannabidiol. Refractory epilepsy.

1. Universidade Católica de Brasília (UCB)

The use of technology as a tool for family intervention during cancer treatment: an experience report

Lavínia Maria Mroz[1]
Fernanda Ribeiro Baptista Marques
Maria Angélica Marcheti
Raissa Maria de Sá Strang

Abstract

Introduction: Both the diagnosis and the treatment of childhood and adolescent cancer cause painful feelings for the child and the family, besides bringing about feelings such as anguish and sadness before the imminent possibility of death. Most of the treatment centers are located in larger cities or capitals, therefore families need to move from their hometowns to receive healthcare, which leads them to be distant from other members, such as a partner and other children, and while they are in their hometowns, they are distant from health professionals. These situations often cause insecurity, and the family needs to receive support and feel strengthened in their potential by the professionals. Facing the need for social isolation due to the coronavirus pandemic, people have used information and communication technologies more frequently. With that, it was possible to bring professionals closer to the families. Thus, we chose to use a smartphone application for video and voice calls as well as sending text messages, videos, images, and documents, as a way to get closer to families and propose interventions that promote resilience, as well as being a space for dialogue for the family to express their feelings and answer questions.

Objective: To report the experience of nursing students in participating in interventions with the family of children in oncologic treatment through a messaging application.

Methods: This is an experience report based on a family intervention conducted by professors of the nursing course, with expertise in family nursing, and students who are members of the 'Laboratório de Estudos e Pesquisa em Intervenção Familiar'. To carry out the interventions, families of children and/or adolescents in oncological treatment assisted by a support home were selected. To conduct the interventions, an application was used in which each family was included and chose the members they would like to participate in the group and their names. The interventions were based on the theoretical Interactional Family Care Model (IFCM), based on the identification of the symbolic definition of the family and the provision of interventions that help to re-signify and relieve suffering, so that it can develop its sense of empowerment to make decisions and modify patterns of functioning in the face of situations experienced (Marcheti, Mandetta, 2016).

Results: After the interventions, the students reported their perceptions on the use of this tool, which proves to be a possibility and an important resource to allow the family to have a positive experience. Through the theoretical model, the students noticed how important it is for the family to be at the center of care. Moreover, they were able to analyze the origin of each individual's suffering within the family, as well as to plan together the necessary interventions to help them in this process.

Conclusion: Nursing students understood the importance of including family members in the care process, and how the use of information and communication technology can be an excellent tool in this process, and the way it can be applied in other contexts and in professional life.

Keywords: Nursing. Family nursing. Information. Technology. Communication.

1. Universidade Federal do Mato Grosso do Sul

Transcranial magnetic stimulation for the treatment of children and adolescents with major depression

Mario Augusto Rego de Macedo[1]
Alexandra Fletcher da Rosa
Arthur Dutra do Bomfim
Danielle Lucas Cardoso
Adria Maria Nascimento Junior

Abstract

Introduction: Transcranial magnetic stimulation (TMS) is a non-invasive neurostimulation technique that employs magnetic fields to stimulate nerve cells within the brain. Repetitive TMS has been utilized as an alternative therapy for adults suffering from major depressive disorder (MDD), and who have shown no response to conventional antidepressant medication and psychotherapy. Despite its recognized tolerance, TMS has been associated with certain adverse effects.

Objective and Methods: This paper constitutes a literature review, with the primary aim of examining the efficacy of TMS as a treatment for depression in children and adolescents. To conduct this review, a search of relevant literature was conducted using the databases LILACS, The Lancet, and PubMed. A total of 16 articles were identified that met the inclusion criteria, which required that articles be published between 2019 and 2023 in either Portuguese or English, have open access, and be closely related to the theme of the paper.

Results: To understand the use of TMS, it is essential to examine its mechanism, efficacy, and safety. It appears that magnetic stimulation can alter cortical neurochemistry by modulating GABAergic and Glutamatergic pathways. This modulation is achieved through the excitatory and inhibitory activity of neurotransmitters, which trigger the motor evoked potential (MEP), which can manifest in various brain activity patterns, including intracortical inhibition (ICI), interhemispheric inhibition (IHI), cortical silent period (CSP), intracortical facilitation (ICF), and motor threshold. The ICF pattern is generally considered an excitatory pattern mediated by glutamate, while the ICI and CSP patterns are regarded as inhibitory patterns mediated by GABA. Moreover, in depression disorders, there have been reports of decreased activity in the GABAergic function, characterized by the CSP and ICI patterns. In this context, TMS appears to have the potential to restore normal brain function by compensating inhibited regions through stimulation. Recent studies have shown that the use of 10-Hz TMS in the left dorsolateral prefrontal cortex can result in an efficiency rate of 45.6% over a 6-month period for the treatment of depression and 41.7% for the treatment of treatment-resistant depression in adolescents. Although mild side effects such as headaches, musculoskeletal discomfort, eye pain, and nausea were reported, the chances of more severe side effects were negligible, with a seizure risk of only 0.02%. Additionally, the tolerability of TMS improved by more than 50% over the course of treatment.

Conclusion: The findings of this study indicate that TMS is a valuable treatment option for patients with MDD, as it stimulates GABAergic pathways such as CSP and ICI. Notably, these pathways are inhibitory in nature, which means that TMS serves to stimulate previously repressed regions. Further experimentation has revealed that, despite the occurrence of side effects, TMS is considered a safe method of treatment, even in cases of treatment-resistant depression.

Keywords: Transcranial magnetic stimulation. Children. Adolescent. Safety.

1. UNIEURO

Treatment of gastroesophageal reflux disease in children by Nissen fundoplication, in open or laparoscopic procedure compared to drug treatment

Camilly Vitória Queiroz Lima[1]
Marcos Gabriell Silva Braz
Maria Eduarda Borges Holanda
Letícia Jardim Fatureto Jeronimo
Manoel Eugenio dos Santos Modelli

Abstract

Introduction: In gastroesophageal reflux disease (GERD), the involuntary passage of gastric contents into the esophagus causes negative repercussions on the child's health. For children with GERD associated with severe complications and/or chronic disease, the best therapeutic options are drug treatment with a proton pump inhibitor and anti-reflux surgery. For surgical treatment, the fundoplication technique described by Nissen is the most frequently used in the pediatric age group and can be open or by video laparoscopy.

Aim: To review the results of traditional or laparoscopic Nissen fundoplication for gastroesophageal reflux disease in children, showing the effectiveness and postoperative complications of the procedure compared to drug treatment.

Method: Literature review study by searching the descriptors Nissen fundoplication, gastroesophageal reflux disease, drug therapy, children, laparoscopic fundoplication in PubMed and Scielo databases, in which 896 articles were obtained. Articles published before 2018 and not corresponding to the theme were excluded, leaving a total of 11 published articles.

Results: The objective of the surgery is to stop gastroesophageal reflux through a combination of anti-reflux mechanisms and is recommended for patients with chronic disease, including chronic encephalopathies, patients with chronic respiratory disease or patients operated on for esophageal atresia. In these patients, the risk of postoperative morbidity and surgical failure are higher. The rate of failure of the surgical technique can vary from approximately 5% to 20% of operated children, depending mainly on the presence of the aforementioned associated diseases. Due to the lack of data on the use of drugs in pediatric patients, long-term clinical use is limited. Withdrawal of the drug is followed by recurrence of symptoms in 50% of patients after 6 months and in 100% after 12 months. Therefore, Nissen fundoplication is often recommended to replace the continuous use of proton pump inhibitors, for patients with no response, partial response, or when there is recurrence of symptoms. Compared to open fundoplication, video laparoscopic fundoplication has a shorter recovery time, fewer complications, better aesthetic results and shorter hospital stay, with faster recovery, being the most recommended for the treatment of GERD. From an anatomical point of view, the main causes of recurrence of GERD in the postoperative period are partial or total removal of the fundoplication and, less frequently, the migration of the anti-reflux valve to the thorax.

Conclusion: Surgical treatment proved to be efficient in controlling esophageal complications of gastroesophageal reflux disease in children, especially for patients with chronic diseases, due to limited clinical use for drug treatment. Fundoplication by video laparoscopy is more indicated than the open one due to a lower rate of failure, and consequent decrease in morbidity, despite the possibility of complications such as the removal of the fundoplication and migration of the valve to the thorax. Therefore, it is the most effective alternative to drug treatment and is associated with excellent short– and long-term results.

Keywords: Laparoscopic. Nissen. Fundoplication. Gastroesophageal reflux. Drug. Therapy.

1. Centro Universitário de Brasília (CEUB)

Treatment of Systemic Lupus Erythematosus with Belimumab and the impact of network support on pediatric patients

Lara Isabela Vieira da Cunha[1]
Ana Cecília Amancio Vieira

Abstract

Introduction: Systemic Lupus Erythematosus (SLE) is an autoimmune disease that affects several organs of the human body, characterized by high production of autoantibodies. Children with SLE, compared to adults with the disease, are more likely to develop Lupus Nephritis (LN), a kidney malfunction. Studies used in this review show that Belimumab is a drug aimed at the treatment of SLE and it had satisfactory results. In addition, it will be discussed how health professionals and the support network affect the quality of life of those patients.

Objective: The objective of this study is to find evidence in literature to improve the treatment of SLE in pediatric patients with Belimumab, furthermore, to identify the impact that health providers and the support network can have on those patients.

Methods: This is a review of 7 articles published between 2020 and 2022, found in the databases of PubMed and Scielo, the keywords used were: Systemic Lupus Erythematosus AND pediatric OR network support. Articles that were not written in English and did not have the mentioned descriptors were excluded for this review.

Results: The standard treatment for SLE involves long-term glucocorticoids. As a replacement, the new drug studied, Belimumab, is characterized by being a monoclonal antibody that reduces the number of B cells in the body, and consequently decreases the formation of autoantibodies that trigger inflammatory reactions, the main cause of LES. The proper administration of the medicine in adults or children is 10 mg/kg. With this dose, studies have shown that the progression of SLE and LN is reduced, and it also reduces the dose of glucocorticoids. SLE generates several consequences and also compromises people with this condition, including emotional and psychological distress. Hence, an important strategy for reducing these consequences is the strengthening of technologies and the support network involved in this care. Light technologies, which is, the relationships themselves, are necessary for establishing a bond and welcoming the patient and family involved. From this relationship, adherence to treatment becomes greater which improved results in patients' quality of life. Moreover, the support network needs to be encouraged and trained, with the aim of dealing appropriately with the situation and thus generating better living conditions for SLE patients.

Conclusion: It can be concluded that SLE is an autoimmune disease with several impacts on the lives of patients with it. Despite this, there are treatments to regulate this condition, such as the drug Belimumab. It was possible to observe the great and positive impact that light technologies and the well-applied and trained support network have on the care process of pediatric patients with SLE, highlighting how these aspects result in the improvement of the quality of life of these patients.

Keywords: Lupus erythematosus. Autoantibodies. Glucocorticoids. Pediatrics.

1. Universidade de Brasília (UnB)

Use of internet-based technologies in uropediatrics: scoping review

Erika Lorena Ramos de Oliveira Silva[1]
Samara dos Santos Paiva
Gisele Martins

Abstract

Introduction: Currently, on the world stage, healthcare has been transformed, particularly due to the incorporation of new means, methods and processes brought about by the use of information and communication technologies (ICTs). ICTs encompass the website, email, social media, mobile applications, video calls (which involve telemedicine services and teleassistance), being used as a tool to promote care, especially for patients who need continuous and long-term care. The different specialties in the health area, including pediatric urology, are implementing TBIs as an instrument to improve and support healthcare, to facilitate the exchange of knowledge, offer personalized interventions, in addition to providing autonomy and engagement with long-term healthcare.

Objective: To map the evidence on internet-based technologies and their applicability in outpatient and home care in Pediatric Urology.

Methods: This is a scope review, with searches conducted in 6 databases, with no time limit, in Portuguese, English and Spanish.

Results: 2,200 articles were obtained, with 19 publications eligible for the final sample. The most used internet-based technologies were telehealth and telemedicine (58%), mobile applications (21.05%), online intervention programs (15.79%) and with a lower rate the use of serious games, social media (SoMe) and urination video (5.16% each), mainly in the home environment (89%).

Conclusion: These technologies are promising in the (self)management of uropediatrics patients, in addition to favoring early diagnosis, greater therapeutic adherence, particularly by supporting personalized interventions to the needs of uropediatric patients. ICTs also proved to be facilitators of therapeutic adherence, greater agility in the diagnostic process, as well as implementing more personalized care. Therefore, ICTs favor self-management and self-efficacy skills, simplifying the monitoring and follow-up process of pediatric patients and their families in the areas of education, assistance, and rehabilitation in health, that is, transiting through the different levels of complexity of urological healthcare for children.

Keywords: Ambulatory care. Internet-based intervention. Urology. Pediatrics. Review.

1. Universidade de Brasília (UnB)

Virtual nursing consultations with families of children and adolescents with bladder and bowel dysfunction: experience report on the ENF-UROPED platform

Erika Lorena Ramos de Oliveira Silva[1]
Gisele Martins

Abstract

Introduction: Specialized nursing care for children with bladder and bowel dysfunction (BBD) and their families has been essential to promote understanding of the nature of urinary and bowel symptoms, implement urotherapy interventions necessary for reestablishing functions and the pattern of elimination and carry out regular monitoring of the child and family. Currently, the speed of information and constant changes mobilize the professional nurse in a constant redefinition of care, particularly with the use of different technological tools in healthcare. In this context, mobile applications and virtual platforms have contributed to advances and innovation in care. For example, the ENF-UROPED platform is a virtual platform for self-care supported in uropediatrics, developed in the research, teaching and extension program, linked to the Nursing Department of the Universidade de Brasília (ENF/UnB), which aims to promote excellence and innovation in assessment, diagnosis and management of urinary and intestinal symptoms during childhood and adolescence in the era of Digital Health.

Objective: To describe the experiences of the authors who are nurses about virtual nursing care for children and adolescents with ILD on the ENF-UROPED platform.

Method: This is a descriptive study, of the experience report type, on the virtual nursing consultations carried out on the Enf-Uroped platform.

Results: Virtual consultations consisted of an innovative method in nursing care for patients with ILD and their families, helping them with supported self-care and promoting access to information and health education, in a customized way for each case. There was a strengthening of the bond with pediatric patients/family members and nurses, in addition to offering individualized care. There was also the possibility of exploring different symptom management strategies in the self-management of DVI.

Conclusion: this experience report opens new perspectives for the practice of virtual care, particularly in nursing care in Pediatric Uropediatrics.

Keywords: Adolescent. Child. Nursing. Family. Internet-based intervention. Educational technology. Urology.

1. Universidade de Brasília (UnB)

Wilson's disease in pediatric patients

Clarice de Abreu Pereira
Gabriela Ponte do Couto
Letícia Mello Matos
Raquel Rodrigues Fonseca da Cunha
Ingrid Reis Abrante
Larissa Neris Oliveira
Luana de Oliveira Pires
Carlos Eduardo Mendes Gomes

Abstract

Introduction: Wilson's disease is a rare condition, with an autosomal recessive character, defined by an accumulation of copper in the liver. It is the result of a mutation in the ATP7B gene that encodes the P-type ATPase, responsible for copper excretion, which becomes impaired by increasing its concentration mainly in the liver, and can also affect other organs and tissues, including the brain and cornea.

Objective: Report the systemic presentations and laboratory alterations for the diagnosis and treatment of Wilson's disease in pediatric patients.

Methodology: This is an integrative literature review, whose research was carried out through scientific journals on PubMed and Scielo platforms in the range of 2008 to 2022.

Results: Wilson's disease has a wide range of symptoms associated with the affected tissue and organ, and can start at any age, predominantly between 5 and 35 years. In pediatric patients, the main manifestation is in the liver, with the presence of cirrhosis and may progress to liver failure. Neuropsychiatric symptoms occur when copper is concentrated in brain tissue, with possible presence of ataxia, tremors, and dystonia. Early diagnosis is hampered by the extent of these symptoms, presenting hepatic manifestations common to other more prevalent pathologies. According to SÓCIO et al, the main laboratory findings for the diagnosis are the elevation of AST, ALT, and indirect bilirubin. Urinary copper dosage averaging 27 mcg/dL. Ceruloplasmin ranging from 1 to 47mg/dL. Drug treatment is administered with D-penicillamine with transient side effects, without the need to suspend or change medication.

Conclusion: Wilson's disease is a rare condition in pediatric patients. Due to the lack of presentation of expected laboratory and clinical changes, early diagnosis becomes a challenge. In pediatrics, Wilson's disease has the predominant form of presentation in the liver, and the development of neuropsychiatric disease is rare in children under 18 years. Diagnosis is based primarily on low ceruloplasmin, free copper, and increased 24-hour urine copper. They show good acceptance of drug treatment with the use of D-penicillamine.

Keywords: Wilson's disease. Pediatrics. Hepatolenticular degeneration.

List of Authors

C

D

E

F

G

H

I

J

K

L

M

N

O

P

Q

R

S

Este livro foi composto em Dante MT
pela Editora Autografia e impresso
em papel pólen natural 80 g/m².

ISBN 978-85-93386-17-6

REALIZAÇÃO:

SJD Sant Joan de Déu Barcelona · Hospital

HOSPITAL DA CRIANÇA DE BRASÍLIA JOSÉ ALENCAR

icipe INSTITUTO DO CÂNCER INFANTIL E PEDIATRIA ESPECIALIZADA

Secretaria de Saúde GOVERNO DO DISTRITO FEDERAL

SUS