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(Organizadora)

Cuidados Paliativos: Procedimentos para Melhores Práticas

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Yvanna Carla de Souza Salgado
(Organizadora)

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APRESENTAÇÃO

A obra “**CUIDADOS PALIATIVOS: PROCEDIMENTOS PARA MELHORES PRÁTICAS**” aborda artigos relacionados aos cuidados paliativos, que são oferecidos aos pacientes que possuem uma doença não passível de cura; visando melhor qualidade de vida através da prevenção e alívio do sofrimento para que possam viver o mais confortavelmente possível.

Para que os resultados sejam satisfatórios, busca-se uma abordagem multiprofissional focada não somente nas necessidades dos pacientes, como também na de seus familiares. A Organização Mundial da Saúde define Cuidados Paliativos como a *“abordagem que promove a qualidade de vida de pacientes e seus familiares, que enfrentam doenças que ameacem a continuidade da vida, através da prevenção e alívio do sofrimento. Requer a identificação precoce, avaliação e tratamento da dor e outros problemas de natureza física, psicossocial e espiritual”*.

A obra possui o intuito de ampliar o conhecimento da temática, contribuindo assim para a formulação de políticas públicas, elaboração de protocolos e ferramentas de levantamento de dados, levantamento das questões éticas relacionadas à assistência e aprofundamento da compreensão da importância destes cuidados.

A obra é fruto do esforço e dedicação das pesquisas dos autores e colaboradores de cada capítulo e da Atena Editora em elaborar este projeto de disseminação de conhecimento e da pesquisa brasileira. Espero que este livro possa permitir uma visão geral e inspirar os leitores a contribuírem com pesquisas para a promoção da saúde e bem estar social.

Yvanna Carla de Souza Salgado

SUMÁRIO

CAPÍTULO 1	1
ACOLHIMENTO COMO TECNOLOGIA LEVE NA ATENÇÃO PRIMÁRIA	
<i>Vitória Eduarda Silva Rodrigues</i>	
<i>Francisco Gerlai Lima Oliveira</i>	
<i>Denival Nascimento Vieira Júnior</i>	
<i>Sara Joana Serra Ribeiro</i>	
<i>Brenda Moreira Loiola</i>	
<i>Camila Carvalho dos Santos</i>	
<i>Waléria Geovana dos Santos Sousa</i>	
<i>Manoel Renan de Sousa Carvalho</i>	
<i>Gabriela Maria da Conceição</i>	
<i>Sarah Nilkece Mesquita Araújo Nogueira Bastos</i>	
DOI 10.22533/at.ed.4641920081	
CAPÍTULO 2	13
CUIDADOS PALIATIVOS NA ATENÇÃO PRIMÁRIA À SAÚDE	
<i>Luís Paulo Souza e Souza</i>	
<i>Gabriel Silvestre Minucci</i>	
<i>Patrícia Silva Rodríguez</i>	
<i>Tamara Figueiredo</i>	
DOI 10.22533/at.ed.4641920082	
CAPÍTULO 3	20
ASSISTÊNCIA DE ENFERMAGEM À CRIANÇA EM CUIDADOS PALIATIVOS	
<i>Maria Lúcia de Mendonça Sandes</i>	
<i>Thiago de Sá Samuel</i>	
<i>Karla Fernanda Batista</i>	
<i>Maiara dos Santos Pereira</i>	
<i>Anna Beatriz Fernandes Bezerra Santos</i>	
<i>Monica Santos Teles</i>	
<i>Mayara de Jesus Silva</i>	
<i>Heryca Natacha Cruz Santos</i>	
<i>Priscila dos Santos Nascimento Gonçalves</i>	
<i>Michelly Karolaynny dos Santos</i>	
<i>Marília de Oliveira Santos</i>	
DOI 10.22533/at.ed.4641920083	
CAPÍTULO 4	31
AVALIAÇÃO PSICOMÉTRICA DO TEXAS <i>REVISED INVENTORY OF GRIEF</i> (TRIG) EM PAÍS BRASILEIROS QUE PERDERAM O FILHO COM CÂNCER	
<i>Erica Boldrini</i>	
DOI 10.22533/at.ed.4641920084	
CAPÍTULO 5	42
MEDIDA DO BEM-ESTAR DOS CUIDADORES DE PACIENTES PALIATIVOS ONCOLÓGICOS PEDIÁTRICOS	
<i>Ligiamara de Castro Toledo</i>	
<i>Thiago Buosi da Silva</i>	
<i>Erica Boldrini</i>	
DOI 10.22533/at.ed.4641920085	

CAPÍTULO 6	50
AVALIAÇÃO DE BURNOUT EM COLABORADORES DO HOSPITAL DE CÂNCER INFANTOJUVENIL	
<i>Claudia Lucia Rabatini</i> <i>Erica Boldrini</i>	
DOI 10.22533/at.ed.4641920086	
CAPÍTULO 7	59
PLANILHA DE VISITAS DOMICILIARES: UMA EXPERIÊNCIA BEM-SUCEDIDA NA ATENÇÃO PRIMÁRIA À SAÚDE	
<i>Mauricio Vaillant Amarante</i> <i>Ozinelia Pedroni Batista</i> <i>Camila Lampier Lutzke</i> <i>Shirley Kempin Quiqui</i> <i>Marcelo Luiz Koehler</i>	
DOI 10.22533/at.ed.4641920087	
CAPÍTULO 8	65
AVALIAÇÃO DO GRAU DE CONHECIMENTO ACERCA DE CUIDADOS PALIATIVOS DOS MEDICOS E ENFERMEIROS	
<i>Carlos Augusto Moura Santos Filho</i> <i>Rayanna Souza Santos</i>	
DOI 10.22533/at.ed.4641920088	
CAPÍTULO 9	73
MOMENTO ACOLHER: RELATO DE UMA VIVENCIA JUNTO A FAMÍLIA DO PACIENTE EM CUIDADO PALIATIVO	
<i>Flávia Roberta de Araújo Alves</i>	
DOI 10.22533/at.ed.4641920089	
CAPÍTULO 10	76
CUIDADOS PALIATIVOS: O USO DE PALESTRAS COMO UMA DAS FERRAMENTAS/ INFORMATIVO, ESCLARECEDORA-REVISÃO DE PALESTRAS NO CANAL YOUTUBE NO BRASIL	
<i>Marilza Alves de Souza</i> <i>Marília Aguiar</i>	
DOI 10.22533/at.ed.46419200819	
CAPÍTULO 11	88
ASPECTOS BIOÉTICOS RELACIONADOS ÀS PRÁTICAS ASSISTENCIAIS EM FIM DE VIDA	
<i>Paula Christina Pires Muller Maingué</i> <i>Carla Corradi Perini</i> <i>Andréa Pires Muller</i>	
DOI 10.22533/at.ed.46419200811	

CAPÍTULO 12 97

O PACIENTE EM SUA FASE FINAL: O FISIOTERAPEUTA PODE AJUDÁ-LO NESSE PROCESSO?

Bárbara Carvalho dos Santos
Francelly Carvalho dos Santos
Brena Costa de Oliveira
Suellen Aparecida Patricio Pereira
Roniel Alef de Oliveira Costa
Kledson Amaro de Moura Fé
Edilene Rocha de Sousa
Joana Maria da Silva Guimarães
Laércio Bruno Ferreira Martins
Daccione Ramos da Conceição
Maylla Salete Rocha Santos Chaves
Fabriza Maria da Conceição Lopes
David Reis Moura

DOI 10.22533/at.ed.46419200812

CAPÍTULO 13 107

VIVÊNCIAS E NECESSIDADES DOS CUIDADORES FAMILIARES DE IDOSOS COM DOENÇA DE ALZHEIMER

Danilo Ferreira Santos
José Lucas Fagundes de Souza
Aparecida Samanta Lima Gonçalves
Valdira Vieira de Oliveira
Júlia de Oliveira e Silva
Gabriel Silvestre Minucci
Luís Paulo Souza e Souza
Rosana Franciele Botelho Ruas

DOI 10.22533/at.ed.46419200813

CAPÍTULO 14 121

PERCEPÇÃO DOS PROFISSIONAIS DA SAÚDE ACERCA DA ORTOTANÁSIA

Ana Dagnaria Rocha
Claudiane Aparecida Guimarães

DOI 10.22533/at.ed.46419200814

CAPÍTULO 15 133

ESTUDO SOBRE OS FATORES ASSOCIADOS AO LOCAL DE ÓBITO DE PACIENTES ONCOLÓGICOS, ENTRE 2007-2016, NA CIDADE DE BELO HORIZONTE

Izabela Fuentes
Marcelle Ferreira Saldanha
Thais Therezinha Duarte Marques
Eliene Antonieta Diniz e Asevedo
Jéssica da Silva Andrade Medeiros
Samuel Ribeiro Dias
Tassiano Vieira de Souza

DOI 10.22533/at.ed.46419200815

CAPÍTULO 16	138
CONHECIMENTOS E PRÁTICAS DE MÉDICOS DO IMIP SOBRE DIRETIVAS ANTECIPADAS DE VONTADE: “CORTE TRANSVERSAL”	
<i>Nicolle Galiza Simões</i>	
<i>Ana Karla Almeida de Macedo</i>	
<i>Bruna Priscila Dornelas da Silva</i>	
<i>Flávia Augusta de Orange</i>	
<i>Mirella Rebello Bezerra</i>	
<i>Jurema Telles de Oliveira Lima</i>	
DOI 10.22533/at.ed.46419200816	
CAPÍTULO 17	153
RELATO DE CASO: IMPLANTAÇÃO DO ENSINO EM CUIDADOS PALIATIVOS NA UNIVERSIDADE DO ESTADO DO RIO DE JANEIRO	
<i>Andrea Augusta Castro</i>	
<i>Natan Iorio Marques</i>	
DOI 10.22533/at.ed.46419200817	
CAPÍTULO 18	170
PALLIATIVE CARE IN CONGENITAL SYNDROME OF THE ZIKA VIRUS ASSOCIATED WITH HOSPITALIZATION AND EMERGENCY CONSULTATION	
<i>Aline Maria de Oliveira Rocha</i>	
<i>Maria Julia Gonçalves de Mello</i>	
<i>Juliane Roberta Dias Torres</i>	
<i>Natalia de Oliveira Valença</i>	
<i>Alessandra Costa de Azevedo Maia</i>	
<i>Nara Vasconcelos Cavalcanti</i>	
DOI 10.22533/at.ed.46419200818	
CAPÍTULO 19	182
SÍNDROME DO ESGOTAMENTO PROFISSIONAL (<i>BURNOUT</i>) EM UM HOSPITAL DE CUIDADOS PALIATIVOS: O CUIDADO COMO FATOR DE RISCO	
<i>Manuela Samir Maciel Salman</i>	
<i>Diana Mohamed Salman</i>	
<i>Thiago Vinicius Monteleone Lira</i>	
DOI 10.22533/at.ed.46419200819	
SOBRE A ORGANIZADORA	194
ÍNDICE REMISSIVO	195

PALLIATIVE CARE IN CONGENITAL SYNDROME OF THE ZIKA VIRUS ASSOCIATED WITH HOSPITALIZATION AND EMERGENCY CONSULTATION

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CUIDADOS PALIATIVOS NA SÍNDROME CONGÊNITA DO ZIKA VÍRUS ASSOCIADO À HOSPITALIZAÇÃO E CONSULTA DE PRONTO ATENDIMENTO

ABSTRACT: **Background:** Congenital syndrome of zika virus (CSZV) is associated with neuromotor and cognitive developmental disorders, limiting the independence and autonomy of affected children and high susceptibility to complications, so palliative care needs to be discussed and applied. **Aim:** Identify factors associated with emergency

visits and hospitalizations of patients with CSZV and clinical interventions performed from the perspective of palliative care. **Design:** Cross-sectional study with bidirectional longitudinal component. Data were collected between May and October 2017 through the review of medical records and interviews with relatives of patients hospitalized. Setting/Participants: Developed in a tertiary care hospital involving patients with confirmed CSZV born as of August 2015 and followed up until October 2017. Patients under investigation were excluded. **Results:** 145 patients were followed up at the specialized outpatient clinic and 92 (63.5%) were consulted at least once in the emergency room, 49% already had been hospitalized, the main reason being neurological causes, while 24.1% had never require any emergency visit or hospitalization. No risk factors were associated with the occurrence of consultations or hospitalizations. Such events happened at an early age and were accompanied by a high number of invasive procedures and interventions. An approach in palliative care was only identified in two hospitalized patients. **Conclusions:** For the patient with known severe malformations caused by congenital infection by the zika virus with indication of palliative care, this approach could be used in order to allow life without suffering and disproportionate invasive method.

KEYWORDS: Microcephaly; Zika virus; Palliative care; Hospitalization.

INTRODUCTION

Between August and November 2015, a substantial increase in the number of cases of newborns with microcephaly (Ministry of Health, 2015), characterized by the World Health Organization (WHO) as an “anomaly in which the head circumference (HC) is less than two or more standard deviations than the reference for sex, age or gestational age” (WHO, 2015).

This clinical condition leads to medicalization, hospitalization and invasive procedures such as ventriculo-peritoneal shunt (VPS) and gastrostomy. The innumerable associated morbidities and limited quality of life emphasize the need to discuss palliative care in this group (Teixeira *et al*, 2016; Iglesias *et al*, 2016, Carvalho 2012; Chambers, 2003).

The prevalence of congenital microcephaly in Brazil was estimated at 1.98 per 10,000 live births by October 2015, a number that increased 3 to 12 times during the microcephaly outbreak, depending on the region considered (Ministry of Health, 2015). The majority of these patients were concentrated in the state of Pernambuco (State Secretariat of Health of Pernambuco, 2015).

It was possible to correlate such an aggravation to the infection by zika virus during pregnancy and may result in miscarriage, fetal death or congenital anomalies in several organs, being characterized as Congenital Syndrome of Zika virus (CSZV) (Araujo *et al*, 2017). CSZV has become a clinical condition associated with several complications, with a disabling and non-curable nature (Schaub *et al*, 2017).

Palliative care is understood as active and total approach to care, which begins from diagnosis of life-limiting or life-threatening conditions and continues throughout the child’s life and death (Possas *et al*, 2017).

In pediatrics it should be considered for “complex chronic clinical conditions”, defined as situations that present at least 12 months of survival and affect one or more organ systems that require specialized pediatric care (Iglesias *et al*, 2016, Carvalho 2012; Chambers, 2003). What is aimed is the best quality of life for the patient and his family, attending to the physical, psychological, spiritual and social needs.

However, there were no studies in the researched literature (PubMed, SciELO and LILACS) that discussed the adoption of palliative care in this population or articles that analyzed data on hospitalizations or search for emergency care services.

The goal of the present study was to determine the frequency and factors associated with hospitalization and emergency care of patients with CSZV, in addition to observing the interventions performed at these moments, analyzing them according to the perspective of palliative care.

MATERIAL AND METHODS

A cross-sectional observational study with internal comparison group and bidirectional longitudinal component (concurrent and non-concurrent) involving patients with CSZV. The research involved patients born with CSZV as of August 2015 and followed up until October 2017 and data collection occurred between May and October 2017.

Patients with characteristic neurological images on computed tomography (CT) and magnetic resonance (MR) and/or positive IgM serology for Zika virus in cerebrospinal fluid (CSF) were included. A list of patients accompanied at the clinic specialized in CSZV was made, followed by an analysis of the medical records and a search in the hospital's internal information system.

In the prospective component of the research, the inpatients' companions were informed about the purpose of the study and, upon agreeing to participate, a free informed consent form was requested, and the questioner was completed by interview and analysis of medical records.

Data accuracy was ascertained by double entry of all data obtained in the program Microsoft Excel, exported and compared in order to correct inconsistencies. Epi Info 5.4 and GraphPad Prism 7.0 software were employed for statistical analysis.

The association between categorical variables was assessed by calculating odds ratio and Chi-square test or by Fisher's exact test, where relevant. For the numerical variables, the Shapiro-Wilk's test was initially applied. The non-parametric Mann-Whitney test was used to compare numerical variables with non-normal distribution between two groups, while Student's t-test was used to compare variables with normal distribution. A p value less than 0.05 was considered significant.

This project was approved by IMIP's Ethics Committee in Research under protocol no. 54701516.1.0000.5201.

RESULTS AND DISCUSSION

A total of 145 patients were identified in our specialized clinic. Of these, 74 (51.0%) maintained regular follow-up, 41 (28.2%) were transferred to follow-up clinic near the home city or to other referral centers in the metropolitan region, 5 (3.5%) died and 25 (17.2%) lost follow-up in this period. The maternal and the patients with CSZV characteristics are presented in table 1.

Maternal Characteristics	N (%)	Patients with CSZV	N (%)
		• Female	78 (53.8)
• Schooling (years)		• Head circumference at birth (Z score for age and sex)	
≤ 4	3 (2.1)	< z -3	101 (69.5)
5-9	4 4 (30.3)	z-3 to z-2	21 (14.5)
10-11	6 4 (44.1)	z-2 to z-1	13 (9.0)
≥ 12	10 (6.9)	> z -1	10 (7.0)
No registry	2 4 (16.6)	• Age (months)	25 (17.3)
		<12m	39 (26.9)
		12-18m	81 (55.8)
		>18m	92 (63.5)
• From MRR^a	6 8 (46.9)	• Consultation in emergency care	92 (63.5)
• Occupation		• Hospitalization	71 (49.0)
Housewives	8 5 (58.6)	➤ Causes of hospitalization	
Formal Work	1 8 (12.4)	Neurological Causes	24 (33.8)
Informal Work	14 (9.7)	Invasive procedures ^b	14 (19.8)
Student	6 (4.1)	Respiratory infections	6 (8.5)
No data	2 2 (15.2)	Wheezing	4 (5.6)
		Dysphagia	1 (1.4)
		Others	18 (25.3)
		No registry	4 (5.6)
• Age (years)		➤ Length of hospitalization (days)	
≤17	1 5 (10.3)	≤ 1	12 (16.9)
18-24	6 2 (42.8)	2-7	46 (64.8)
25 - 34 years	5 6 (38.6)	8 -14	8 (11.3)
≥35 years	11 (7.6)	15 - 30	4 (5.6)
No registry	1 (0.7)	> 30	1 (1.4)

Table 1. Maternal and patients with CZVS characteristics. Institute of Integral Medicine Prof. Fernando Figueira - August 2015 to October 2017.

a - Metropolitan Region of Recife

b - Described as invasive procedures: peritoneal ventricle shunt, gastrostomy, herniorrhaphy, postectomy.

Most mothers (58.6%) were housewives and it was observed during the review of records and individual interviews that many mothers who had formal or informal work outside the home before the birth of these children had to leave their previous jobs to dedicate themselves to looking after the children.

The low age of progenitors was consistent with findings in other studies (Melo *et al*, 2016; Pan-American Health Organization, 2015; Neta, 2016), demonstrating the reality of young mothers who need to dedicate special attention to children with different needs (Campo, 2017; Alves, 2016; Botelho, 2016). Most mothers were housewives and despite receiving government financial benefit, the costs associated with the care required by these children are quite high, such as transportation, medical care, medications, rehabilitation, among others (Gomes, 2016).

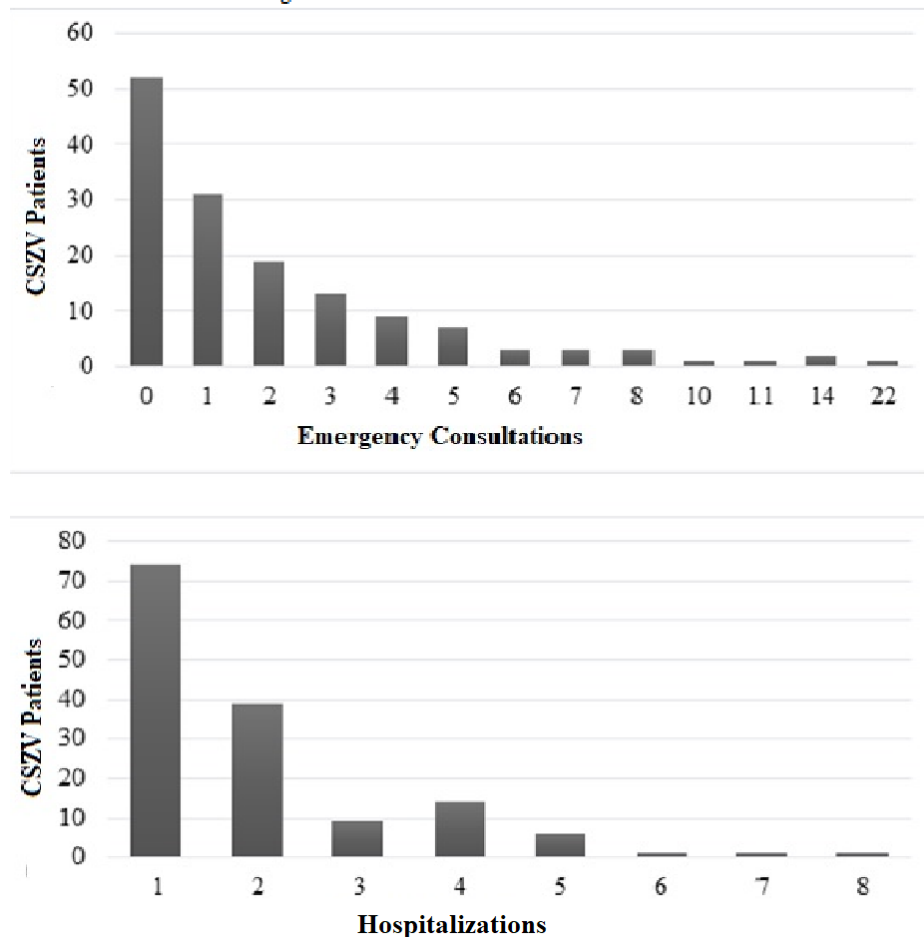
The HC at birth was between 22 and 34 cm with a mean of 28.9 cm (standard deviation - SD \pm 2.1). All patients underwent cranial tomography and 110 (75.9%) performed CSF's collect. Most patients (76.6%) had changes in CT considered suggestive of CSZV, but with a negative CSF serology for zika virus; one had no characteristic CT changes but positive CSF serology and 22.8% had characteristic changes both in the tomography and CSF serology positivity.

In the service, 313 consultations regarding patients with CSZV were identified. Among the 92 patients who were consulted in the emergency service between the neonatal period and 20 months of age, the average was 7 months of age and the maximum number of visits per patient was 22 times. About 1/3 (36.5%) of the children in regular follow-up never needed this type of care.

Despite the lack of data on the occurrence of consultations in other emergency services, it is understood that the high number of consultations in this group is associated with the complications of CSZV such as dysphagia, neurological conditions, irritability, among others, as described in several studies (Aragão *et al*, 2017).

It was observed that patients from Metropolitan Region of Recife (MRR) had more consultations in emergency services, which can be attributed to the ease of access to the service, but this finding did not present a statistically significant difference.

Figure 1. Number of emergency visits and admissions of patients with CZVS up to 25 months of life. IMIP - August 2015 to October 2017.



In total, 143 hospitalizations were analyzed. The first hospitalization occurred from the neonatal period up to the full 24 months, with an average of 7 months. Half of the patients (51%) never needed to be hospitalized, and the number of hospitalizations per patient ranged from one (26.2%) to eight (0.7%). The main cause of the first hospitalization was a neurological condition associated with CSZV (42.2%) and described in medical records such as microcephaly, hydrocephalus, seizures or somnolence due to intracranial hypertension (Gomes *et al*, 2016; Alves *et al*, 2016).

Observational studies have shown an evolution for hydrocephalus in approximately 41% of patients with CSZV in the first 17 months of life, with an indication of VPS in all of these (França *et al*, 2017).

The hospitalizations occurred to perform invasive procedures (9.7%) such as VPS implantation, gastrostomy or orthopedic surgeries due to complications inherent to the basis disease. Respiratory infections accounted for 4.1% of hospitalizations of these children, understood as possible consequences of broncho-aspirations due to neurological disorders and swallowing. As observed in other studies, this pattern of complications would be expected for these children, however, the high number of hospitalizations and invasive procedures stands out (Campo *et al*, 2017; Alves *et al*, 2016; Botelho *et al*, 2016, Gomes *et al*, 2016).

The duration of hospitalization was between one and 39 days, with an average

of four days. Those who were discharged on the same day had been admitted for minor surgical procedures, such as herniorrhaphy or postectomy. The discharge from the hospital occurred by improvement (93%), transfer (6.3%) and death (0.7%).

Prolonged admissions, call the attention to the potential for complications, especially in relation to healthcare-associated infections, to the change in family dynamics in this period, compromising the patient and family's quality of life, in addition to the high cost to the health system (Chanes & Monsores, 2016).

Risk factors for inpatient and outpatient emergency's consultation were analyzed comparing them to the non-hospitalized and non-urgently consulted groups, both with CSZV. Among the variables studied, no factor was associated with the higher occurrence of hospitalizations or consultations in the emergency room, as it can be observed on table 2.

Variables	EMERGENCY CONSULTS		PR ^b (95% RI)	P
	Yes N (%)	No N (%)		
	92 (63.4)	53 (36.6)		
Maternal education <10 years	35 (42.2)	12 (31.6)	1.18 (0.89 -1.57)	0.36
Gender (Female)	52 (56.5)	27 (50.9)	1.17 (0.82-1.66)	0.48
Maternal occupation (From home)	64 (77.1)	27 (67.5)	1.41 (0.78-2.57)	0.35
Maternal age (Median)	24	23		0.57
Origin (MRR / Interior) ^{to}	49/43	19/34	0.67 (0.44 - 1.01)	0.06
Head circumference (Mean)	28.8 4 (± 0.27)	29.01 (± 0.23)	1.30 (0.57 - 1.91)	0.64

Variables	HOSPITAL ADMISSION		PR (95% CI)	P
	Yes N (%)	No N (%)		
	71 (49.0)	74 (51.0)		
Maternal education <10 years	24 (38.1)	23 (39.7)	0.97 (0.73-1.29)	0.99
Gender (Male / Female)	36/35	31/43	0.82 (0.58-1.17)	0.36
Maternal occupation (From home)	49 (75.4)	42 (72.4)	1.12 (0.61-2.03)	0.86
Maternal age (Median)	24	24		0.72
Origin (MRR / Interior)	36/35	32/42	0.85 (0.60 to 1.20)	0.46
Head circumference (Mean)	28.97 (± 0.24)	28.93 (± 0.26)	1.16 (0.66 to 1.76)	0.89

Table 2. Univariate analysis of the possible factors associated with emergency visits and hospitalization in patients with SCZV. Institute of Integral Medicine Prof. Fernando Figueira - August 2015 to October 2017.

a - Metropolitan Region of Recife.

b - Statistical analysis: PR = prevalence ratio, p according to Fisher's exact test for categorical variables, Mann Whitney for non-normal continuous and Student's variables for normal continuous variables (Head circumference).

It was possible to observe hospitalizations of 13 patients prospectively and the data are shown on table 3. Of the hospitalized patients, eight were females, the HC of birth was between 28 and 32 cm (average of 29.3 cm and SD \pm 1.0) and the age at admission was between 16 and 24 full months (average of 20 months).

Almost all these patients (92.3%) underwent invasive procedures during hospitalization, the most common being peripheral venous puncture (92.3%), but nasogastric tube (NGT) was also used in 46.1% (six patients), the central venous puncture in 15.4% (two patients), the use of gastrostomy by a patient (7.7%) and oxygen support at 46.1% (six) of patients, ranging from oxygen catheter to orotracheal intubation in an emergency room in one of the patients (7.7%).

It was possible to observe, with emphasis on the analysis of aspects related to palliative care, the high occurrence of invasive procedures. Such procedures provoke pain during its accomplishment and discomfort during the period of use. Moreover, invasive devices can facilitate colonization by nosocomial bacterias and cause local and systemic infections. Therefore, procedures may become useless and an idle cause of suffering if they are not indicated (Chanes & Monsores, 2016).

Functional assessments according to the Lansky scale[19] based on neurological evaluation and accompanying reports were recorded. The largest evaluation was quantified in "40" for two (15.4%) of the patients (participates in quiet activities), four (30.8%) had their functional evaluation in class "30" (needs assistance even for quiet activity) and the others (53.8%) had a quantified "20" evaluation (play is entirely limited to very passive activities). This tool is an auxiliary measure in the elaboration of the care plan for these patients and showed the limitation regarding activities of daily living and absence of autonomy of these patients.

Two (15.4%) of the patients had their records requested for a first-time ICU vacancy, both due to acute respiratory failure. After a better understanding by the medical team that assisted them regarding the functionality, characterization of the clinical condition and associated with the basis disease, the request for a vacancy in the ICU was suspended and after conversation and clarification with companions, palliative care measures were indicated: patient number three was submitted to palliative extubation according to precepts of palliative care and airway support was installed with continuous positive pressure and patient number nine had the bladder catheter of delay and central venous access removed; for both the order of non-resuscitation was expressed and symptom control measures were performed (analgesia).

Patient	Maternal Age (years)	Maternal Education (years)	Mother Occupation	From	Sex	HC birth (cm)	Age (months)	Diagnosis ^a	Duration (days)	Device ^d	ICU Indic (Y/N)	CCPP (Y/N)	Output	Scale of Lansky
1	19	10	Hou-sewife	MRR	M	29	20	Respiratory Infection	4	NGT, PVP, Catheter O2	N	N	Discharge	30
2	21	11	Hou-sewife	MRR	M	30	22	Neurological Cause	10	GTT, PVP, Venturi M.	N	N	Discharge	30
3	-	-	Hou-sewife	Interior	M	29	16	Respiratory infection	12	NGT, OTT, PVP, CPAP, Venturi M.	Y	Y	Discharge	20
4	37	12	Hou-sewife	Interior	M	28.5	17	Neurological Cause	1	PVP	N	N	Transf	20
5	21	11	Hou-sewife	MRR	F	30	20	Other ^b	6	-	N	N	Discharge	20
6	18	9	Hou-sewife	MRR	F	28	22	Wheezing	2	PVP	N	N	Discharge	40
7	33	12	Hou-sewife	MRR	F	29	20	Other ^c	4	PVP	N	N	Discharge	30-20
8	31	12	Hou-sewife	MRR	F	30	23	Respiratory infection	2	NGT, PVP, Venturi M.	N	N	Discharge	20
9	23	12	Hou-sewife	Interior	F	29	19	Respiratory infection	10	NGT, DVC, PVP, CVP, CPAP, Venturi M.	Y	Y	Death	20
10	16	8	Hou-sewife	Interior	F	32	20	Respiratory Infection	49	NGT, VPS, PVP, CVP, Venturi M.	N	N	Discharge	30
11	20	12	Hou-sewife	Interior	M	29	21	Neurological Cause	3	NGT, VPS, PVP	N	N	Discharge	20
12	21	10	Hou-sewife	MRR	F	30	24	Resp Infec	3	PVP	N	N	Discharge	40
13	35	9	Hou-sewife	MRR	M	28	21	Resp Infec	5	PVP	N	N	Discharge	30

Table 3. Characteristics of CZVS patients prospectively observed during hospitalization. Institute of Integral Medicine Prof. Fernando Figueira - May to October 2017.

a - Diagnoses were divided into categories: Respiratory infections (upper and lower airways); Neurological causes (epileptic seizures, irritability, hydrocephalus); Wheezing; Others.

b - Other: Conjunctivitis.

c - Other: Fever without localized signs.

d - Abbreviation of devices: nasogastric tube (NGT), peripheral venous puncture (PVP), central venous puncture (CVP), gastrostomy (GTT), orotracheal tube (OTT), Continuous Positive Airway Pressure (CPAP), Venturi mask (Venturi M.), Delay vesical catheter (DVC), ventriculo-peritoneal shunt (VPS).

e - Acronyms / Abbreviations: Metropolitan Region of Recife (MRR) Transference (Transf) , Male/Female (M/F), Yes/No (Y N), Indicates Intensive Care Unit (ICU Indic), Palliative Care (CCPP) .

The need to perform surgical interventions and long hospitalizations in ICU is frequent in children born with malformations, which implies in thinking about the limits of the therapeutic effort in these cases (Chanes & Monsorens, 2016). According to precepts of palliative care, obstinate therapeutic investments in patients without a

cure perspective, such as the cases demonstrated above, should be avoided, but in practice many ICU beds are occupied, sometimes through judicial action, by patients with no possibility of therapeutic control and with underlying diseases that limit survival and interfere greatly in the quality of life, such as CSZV (Chanes & Monsores, 2016). During the observation of hospitalizations, it was seen that the indication of ICU treatment can be reversed and patients received measures to minimize suffering, avoiding painful interventions, as well as being accompanied by family throughout the hospitalization period, including the evolution to death .

The other patient with indication of palliative measures received discharge from hospital with written guidelines in summary over the care plan that was drawn up during and after hospitalization. The remaining patients were discharged and there was no report or description of approach in palliative care intended for them.

CONCLUSIONS

Despite the short life span of children with CSZV, it could be observed through this study that they were submitted to a high number of emergency room visits, as well as hospitalizations with excessive amounts of invasive procedures. It is understood that the patient with severe malformations already known as those caused by congenital infection by zika virus could be identified early for care that would allow life without suffering and without any disproportionate invasive method.

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DECLARATION OF CONFLICTING INTERESTS

The Authors declares that there is no conflict of interest.

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ÍNDICE REMISSIVO

A

Acolhimento 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 16, 29, 74, 78, 85, 117

Assistência à saúde 1, 4, 14, 16, 160, 165

Assistência integral à saúde 3, 108

B

Burnout 50, 51, 52, 53, 54, 55, 56, 57, 58, 182, 183, 184, 185, 186, 187, 188, 189, 190, 191, 192, 193

C

Câncer 23, 24, 29, 31, 33, 35, 36, 39, 40, 42, 43, 45, 46, 47, 48, 50, 55, 56, 57, 58, 73, 74, 99, 100, 101, 104, 105, 122, 131, 134, 135, 136, 137, 156

Conhecimento 5, 2, 5, 6, 12, 28, 65, 66, 67, 69, 70, 71, 72, 77, 84, 86, 88, 90, 93, 114, 115, 116, 121, 122, 126, 131, 140, 141, 143, 145, 156, 157, 158, 160

Criança 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 38, 41, 42, 43, 50

Cuidadores 15, 17, 31, 34, 35, 36, 38, 39, 42, 44, 45, 46, 47, 48, 93, 98, 102, 107, 108, 109, 110, 111, 112, 113, 114, 115, 116, 117, 118, 119, 120, 140, 158, 190

Cuidados de enfermagem 3, 21, 22

Cuidados paliativos 5, 15, 16, 18, 19, 20, 21, 22, 23, 24, 26, 28, 29, 30, 31, 32, 35, 36, 37, 38, 40, 42, 43, 44, 46, 47, 48, 52, 59, 61, 65, 67, 69, 72, 73, 74, 75, 77, 78, 79, 80, 83, 84, 85, 86, 87, 89, 95, 96, 97, 99, 100, 101, 103, 104, 105, 106, 130, 131, 134, 137, 139, 140, 141, 153, 154, 155, 156, 157, 158, 159, 160, 161, 162, 163, 164, 165, 166, 167, 168, 169, 192, 193

D

Doença de Alzheimer 107, 108, 109, 111, 115, 117, 118, 119, 120

Doenças crônicas 16, 59, 61, 86, 94, 98, 99, 140, 154, 155, 185, 190

E

Enfermeiros 5, 11, 23, 26, 29, 30, 52, 65, 66, 68, 69, 70, 84, 96, 99, 101, 114, 121, 125, 129, 131, 192

Esgotamento profissional 54, 182, 183, 184, 185, 188, 189

F

Fisioterapia 97, 106, 124

L

Luto 17, 23, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 67, 73, 74, 79, 84, 86, 162, 182, 184

M

Médicos 6, 19, 36, 38, 52, 58, 65, 66, 68, 69, 70, 76, 80, 91, 92, 95, 99, 101, 121, 125, 127, 128, 132, 138, 140, 141, 142, 143, 144, 145, 156, 158, 159, 161, 183, 188, 189, 192

Morte 16, 17, 18, 22, 23, 24, 25, 26, 30, 31, 32, 33, 35, 37, 38, 44, 46, 52, 53, 67, 68, 70, 72, 73, 75, 79, 83, 84, 86, 88, 89, 90, 91, 92, 93, 94, 95, 96, 103, 104, 121, 122, 123, 124, 126, 127, 128, 129, 130, 131, 132, 139, 141, 142, 144, 145, 146, 147, 153, 154, 155, 156, 157, 158, 159, 160, 161, 162, 163, 164, 165, 182, 183, 184, 189, 191
Morte digna 16, 23, 26, 30, 89, 90, 92

O

Ortotanásia 22, 23, 29, 70, 83, 95, 96, 121, 123, 124, 126, 127, 128, 130, 131, 132, 155, 158

P

Paciente crítico 98, 100

Pessoal da saúde 121

Planejamento 1, 2, 8, 10, 11, 16, 101, 118, 138, 140, 144, 146, 160, 161

Q

Qualidade da assistência à saúde 1, 2, 4

Qualidade de vida 5, 13, 14, 21, 22, 42, 44, 45, 60, 67, 70, 78, 79, 83, 84, 86, 88, 90, 94, 97, 99, 104, 114, 116, 117, 118, 119, 127, 128, 130, 133, 134, 137, 139, 143, 154, 155, 156, 184

T

Tecnologia 2, 3, 12, 42, 44, 45, 46, 47, 48, 56, 84, 85, 88, 90, 139

U

UTI 26, 35, 56, 88, 90, 91, 93, 94, 95, 98, 100, 101, 102, 104, 126, 127, 142, 192

V

Visita domiciliar 59, 62

Z

Zika virus 9, 170, 171, 172, 174, 179, 180, 181

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