

# Holistic nursing care for children with Guillain-Barré syndrome: a five-year retrospective analysis in five Croatian hospitals

Holistyczna opieka pielęgniarska nad dziećmi z zespołem Guillain-Barré: pięcioletnia analiza retrospektywna w pięciu chorwackich szpitalach

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## STRESZCZENIE

### HOLISTYCZNA OPIEKA PIELĘGNIARSKA NAD DZIEĆMI Z ZESPOŁEM GUILLAIN-BARRÉ: PIĘCIOLETNIA ANALIZA RETROSPEKTYWNA W PIĘCIU CHORWACKICH SZPITALACH

**Cel pracy.** Celem pracy była analiza diagnoz pielęgniarskich ustalanych podczas opieki nad dziećmi z zespołem Guillain-Barré oraz przedstawienie specyfiki holistycznej opieki pediatrycznej.

**Material i metody.** Przeprowadzono retrospektywną analizę dokumentacji pielęgniarskiej 14 dzieci z zespołem Guillain-Barré hospitalizowanych w latach 2015–2019 w pięciu chorwackich szpitalach.

**Wyniki.** Badaniem objęto 10 (71,4%) chłopców i 4 (28,6%) dziewczynki (8 miesięcy – 17 lat). Średni czas hospitalizacji wynosił 12,2 dni. W okresie plateau 5 (35,7%) dzieci miało niewielkie zmiany w świadomości, a 6 (42,9%) wymagało pomocy i/lub nadzoru w wykonywaniu czynności samoopieki. Tlen podano jednemu dziecku, a centralny cewnik żylny (CVC) założono 3 (21,4%) dzieci. Trzydzieści (92,9%) dzieci zgłaszało ból. Ryzyko infekcji odnotowano u 11 (78,6%) dzieci. Nakłucie lędźwiowe wykonano u wszystkich dzieci, natomiast immunoterapię poddano 13 (92,9%) z nich. Opiekę CVC i ćwiczenia oddechowe wykonano u 3 (21,4%) dzieci. Dwoje (14,3%) dzieci wymagało intensywnej opieki.

**Wnioski.** Nieprzewidywalny rozwój i skutki zespołu Guillain-Barré wymagają kompleksowej, holistycznej opieki pediatrycznej, która stanowi dla pielęgniarek istotne wyzwanie zawodowe i osobiste.

**Słowa kluczowe:** zespół Guillain-Barré, holistyczne zdrowie, pielęgniarki, zarządzanie opieką nad pacjentem, pediatria

## ABSTRACT

### HOLISTIC NURSING CARE FOR CHILDREN WITH GUILLAIN-BARRÉ SYNDROME: A FIVE-YEAR RETROSPECTIVE ANALYSIS IN FIVE CROATIAN HOSPITALS

**Aim.** The study aimed to analyze nursing diagnoses defined during the care of children with Guillain-Barré syndrome and to present the specifics of holistic pediatric care.

**Material and methods.** A retrospective analysis of nursing documentation was conducted on 14 children with Guillain-Barré syndrome hospitalized between 2015 and 2019 in five Croatian hospitals.

**Results.** The study included 10 (71.4%) boys and 4 (28.6%) girls (8 months – 17 years of age). The average duration of hospitalization was 12.2 days. At plateau, 5 (35.7%) children had minor changes in consciousness and 6 (42.9%) required assistance and/or some supervision in performing self-care activities. Oxygen was administered to one child, and a central venous catheter (CVC) was placed in 3 (21.4%) children. Thirteen (92.9%) children reported pain. The risk for infection was recorded in 11 (78.6%) children. Lumbar puncture was performed in all children, while immunotherapy was administered to 13 (92.9%) of them. The care of a CVC and breathing exercises were performed in 3 (21.4%) children. Two (14.3%) children required intensive care.

**Conclusions.** The unpredictable development and outcome of the Guillain-Barré syndrome require complex holistic pediatric care that represents a significant professional and personal challenge for the nurses.

**Key words:** Guillain-Barré Syndrome, holistic health, nurses, patient care management, pediatrics

## INTRODUCTION

Guillain-Barré syndrome (GBS) is an acute, immune-mediated polyradiculoneuropathy characterized by autonomic, motor, and sensory symptoms, diminished deep tendon reflexes, and symmetrical ascending weakness [1]. The syndrome affects the myelin sheath, resulting in diffuse demyelination, and axon, leading to a degeneration of the nerve itself [2]. Nowadays, GBS is the most common cause of acute flaccid paralysis in children [2-4]. The incidence of GBS in the pediatric population is 0.5-2 cases / 100,000 [5]. Commonly identified etiologies precipitating GBS include *C. jejuni*, *Cytomegalovirus*, *Human gammaherpesvirus 4*, and *M. pneumoniae* [1,6]. Since GBS has become a rare neurologic complication of severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) [7], the incidence of GBS has increased during SARS-CoV-2 epidemics [8]. The course of the syndrome could be highly unpredictable. Therefore, numerous actual and potential problems are possible in pediatric nursing care (e.g., ineffective breathing pattern, impaired spontaneous ventilation, pain, self-care deficit syndrome, impaired physical mobility, activity intolerance, impaired verbal communication, etc.) [3,9,10]. Unfortunately, deaths have also been reported due to complications of GBS (e.g., autonomic disturbances, respiratory failure, etc.) [9]. These situations require a high level of holism in the nursing assessment of the child's condition, anticipating and identifying possible complications, making decisions, and timely response. Therefore, the care for children with GBS must be based on a high level of nursing competency. However, Kudhaer et al. [11] describe that 80% of the surveyed nurses do not have adequate knowledge about the care for children with GBS, which may present a potential risk in the pediatric clinical setting. Case reports in the field mainly describe the course of GBS in children, diagnostic and therapeutic procedures, and actual nursing diagnoses [3,9] without analyzing risk nursing diagnoses, describing the categorization of children according to the needs for health care, or nurse engagement in health care.

Therefore, this study attempts to overcome this shortcoming by providing an analysis of actual and risk nursing diagnoses with individualized nursing interventions during the care of children with GBS. Also, this study provides insight into the categorization of children with GBS according to the needs for health care. In relation to the Croatian Nursing Council [12], the categorization of children is based on critical factors by theorists V. Henderson [12] and D. E. Orem [12]. Children are classified into four categories: 1) self-care, 2) minimal care, 3) intermediate care, and 4) intensive care. A higher category indicates a poorer condition of a child and a higher level of dependence, as well as a higher quantitative and qualitative need for nurse engagement [12].

## AIM

The main goals of the five-year study in five Croatian hospitals are to analyze actual and risk nursing diagnoses defined during the care for children with GBS and to show specific nursing interventions and categorization of children

according to the needs for health care. The purpose is to gain a deeper insight into the specifics of the holistic approach and the complexity of nursing care for children with GBS.

## MATERIAL AND METHODS

The study was conducted in March and April 2021. A retrospective analysis of the nursing documentation included data from 1<sup>st</sup> January 2015 to 31<sup>st</sup> December 2019, from the pediatric wards of five Croatian hospitals in three of the four largest Croatian cities (Zagreb, Rijeka, Osijek).

To record data from the nursing documentation, we made (in Microsoft Word) and printed a data grid for each child with GBS, consisting of two parts and containing a total of 17 items/questions (closed, single/multiple-choice, and open). The first part of the grid contained items about the general characteristics of children: age and gender. The second part of the grid consisted of questions about specific data from nursing documentation: duration of hospitalization, the etiology of GBS, characteristics of the disease, administered therapy, actual and potential problems, specific nursing interventions, and categorization of children according to the needs for health care.

The data from the nursing documentation was collected and inserted into the grid by the authors of this article with the prior permission of the heads of the institutions. The data from the documentation and the grid ensured continuous anonymity (during the collection and processing of the data and presentation of the study results), and they cannot be used to compromise the children's identity. The personal information of an individual child (name, surname, date of birth, address, name of parent/guardian, etc.) was not inserted into the grid during the data collection phase. Furthermore, no significant date during the child's hospitalization was recorded (date of hospital admission/discharge, changes in health status, etc.). The time component was described as a certain number of days (e.g., duration of child's hospitalization was 13 days). The absence of distribution of children by hospitals in the study results and the comparison of data between hospitals additionally contributes to protecting the anonymity of data and the inability to connect an individual child with a particular hospital.

Descriptive analysis was performed on qualitative variables, and results are presented as a total number and a relative number (percent). The mean was calculated to characterize the average value for quantitative traits; the standard deviation (SD) was used as a measure of dispersion. Statistics are presented descriptively, in tables, and figures. The statistical program IBM SPSS (Statistics for Windows Version 24.0. Armonk, NY: IBM Corp.) was used to analyze the results.

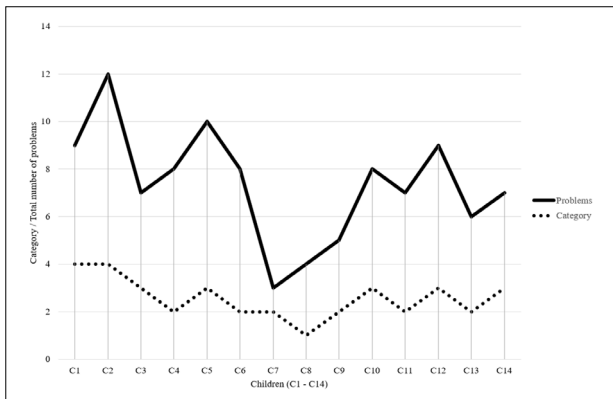
## RESULTS

### General characteristics of the children

The analysis included 14 children of whom 10 (71.4%) were boys, and 4 (28.6%) were girls (Tab. 1.). Children ranged in age from 8 months to 17 years, with a mean of 8.8 (SD = 6.1) years of age. The average duration of hospitalization was 12.2 (SD = 4.9) days (3-20 days).

■ Tab. 1. General characteristics of the children (N=14)

Characteristic	Number (%)
Gender	
Male	10 (71.4)
Female	4 (28.6)
Age (year)	
Infant (< 1)	1 (7.1)
Toddler (1-3)	4 (28.6)
Preschool (4-6)	1 (7.1)
School-aged (7-12)	2 (14.3)
Adolescent (≥ 13)	6 (42.9)



■ Fig 1. Relationship between actual and potential problems and categorization of children according to the needs for health care

■ Tab. 2. Data from nursing documentation (procedures, catheters, consciousness, mobility)

Characteristic	Number (%)
Therapeutic procedures	
Oxygen therapy	1 (7.1)
Endotracheal intubation/Tracheostomy	0
Mechanical ventilation	0
Gastrointestinal tubes	0
Total parenteral nutrition	0
Catheters	
Urinary catheter	1 (7.1)
Central venous catheter	3 (21.4)
Level of consciousness	
Child reacts immediately (eyes open spontaneously, oriented speech, obeys commands)	9 (64.3)
Child responds to verbal stimulus + agitated/drowsy/lightly – moderately sedated	5 (35.7)
Child responds to painful stimulus + agitated/deeply sedated	0
Child is unresponsive to any verbal or physical stimulus and command + combative/highly agitated	0
Mobility	
0 – Completely independent	2 (14.3)
1 – Requires use of assistive device	0
2 – Needs assistance and/or some supervision	6 (42.9)
3 – Needs total supervision	3 (21.4)
4 – Needs total assistance or unable to assist	3 (21.4)

■ Tab. 3. Actual and risk nursing diagnoses in examined children (N=14)

Nursing diagnoses	Children with GBS (C1-C14)													
	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	C12	C13	C14
Self-care deficit syndrome	X	X	X	X	X				X	X	X	X	X	X
Impaired physical mobility	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Activity intolerance	X	X				X		X	X		X	X	X	X
Imbalanced nutrition: Less Than Body Requirements	X	X			X	X								
Impaired swallowing	X	X												
Impaired urinary elimination			X									X		
Diarrhoea				X		X				X				
Ineffective breathing pattern					X									
Impaired verbal communication		X	X			X								
Acute pain	X	X	X	X	X	X	X	X	X	X	X	X		X
Fear/anxiety	X	X		X	X	X		X	X	X	X	X	X	X
Hyperthermia										X				
Risk for infection	X	X	X	X	X	X				X	X	X	X	X
Risk for pressure ulcer/Risk for venous thromboembolism	X	X		X	X							X		X
Risk for aspiration		X												
Risk for injury		X	X	X	X					X	X	X	X	
Risk for falls					X		X							

## Specific data from nursing documentation

Pathogens were isolated in 3 (21.4%) children (*Vari-cella-zoster virus*; *C. jejuni* and *S. enterica*; *M. pneumoniae* and *Human alphaherpes virus 1/2*). Oxygen was administered to one three-year-old child for two days (Tab. 2.). A urinary catheter was placed in 1 (7.1%) child. At plateau, 5 (35.7%) children were agitated/drowsy/lightly – moderately sedated and reacted to verbal stimulus, and 6 (42.9%) required assistance and/or some supervision during everyday self-care activities (feeding, hygiene, dressing, and elimination) (Tab. 2.). According to the categorization, 6 (42.9%) children required minimal care (second category), while 2 (14.3%) children required intensive care (fourth category) (Fig. 1.). All 14 children were discharged after being cured, with no reported health consequences of GBS.

## Actual and potential problems of the children

Impaired physical mobility was recorded in all children, while 11 (78.6%) of them had self-care deficit syndrome (Tab. 3.). Imbalanced nutrition: less than body requirements was recorded in 4 (28.6%) children, while 2 (14.3%) suffered from impaired swallowing. The pain was reported in 13 (92.9%) children. Most children, 12 (85.7%) of them, felt fear or anxiety. The most common potential problem was the risk for infection recorded in 11 (78.6%) children, the risk for aspiration was recorded in 1 (7.1%) child. Multiple problems mainly pointed to a higher category and the need for more sophisticated nursing care (Fig. 1.).

## Specific nursing interventions

Nurses collected cerebrospinal fluid and microbiological/biochemical samples from all children (Tab. 4.). They assessed and treated pain in 13 (92.9%) children, performed interventions before, during, and after numerous diagnostic procedures, and participated in immunotherapy administration.

■ Tab. 4. Specific nursing interventions during health care of children with GBS

Interventions	Number (%)
Microbiological and biochemical sampling	14 (100)
Assisting with lumbar puncture	14 (100)
Identifying non-verbal clinical signs and symptoms of pain	13 (92.9)
Immunotherapy administration (plasma exchange, intravenous immunoglobulin)	13 (92.9)
Preparation (before and after diagnostic procedures), conducting (EEG, ECG, EMNG, etc.)	13 (92.9)
Electrodes and sensors placement on the child's skin	12 (85.7)
Measuring fluid intake and urine output, macroscopic urinalysis	12 (85.7)
Assessing the level of consciousness (AVPU scale, Glasgow coma scale)	11 (78.6)
Capillary blood sampling	9 (64.3)
Care of the central venous catheter	3 (21.4)
Performing chest percussion, practicing postural drainage techniques, breathing, and coughing exercises	3 (21.4)
Testing child's reflexes	3 (21.4)
Oxygen administration (face mask, nasal catheters, etc.)	1 (7.1)
(Assisting with) urinary catheterization, changing catheter drainage bag	1 (7.1)

EEG = electroencephalogram; ECG = electrocardiogram; EMNG = electromyoneurography

## DISCUSSION

A five-year retrospective analysis in five hospitals included 14 children diagnosed with GBS. The incidence of GBS in the world varies, so in children under the age of fifteen in Finland, it is 0.38 cases / 100,000 [13], while in Iran, it is 2.27 cases / 100,000 [13]. The results of this study suggest a more frequent incidence of GBS in males, which follows other studies [14-16], while some literature reports that both genders are equally affected by GBS [10,17]. GBS most commonly affects children aged 1-5 years [4] and is believed to be due to exposure to toxins, infections, and increased susceptibility of young myelin to demyelination [18]. On the other hand, in this study, the highest percentage of affected children are adolescents. This result suggests a possible increase in the incidence rate of GBS with age, as suggested globally by other authors [19,20]. Although GBS is extremely rare in infancy [2,4], this study included one eight-month-old infant. This fact could indicate the unpredictability and severity of the syndrome. The duration of hospitalization of children with GBS mainly depends on the severity of the disease and possible complications [21]. In this study, children were hospitalized for an average of 12.2 days, which is more than the average (8.4 days) in the Turkish study [1], but less than the average (20.4 days) reported by a study conducted in Oman [16]. In two-thirds of cases, GBS is preceded by infections of the respiratory and/or gastrointestinal system [20], while in this study the causative agent of GBS was not isolated in 11 (78.6%) children. The inability to identify the causative agent complicates the process of the treatment and nursing care with significant risks and uncertainties. Recently, several cases of GBS in children were reported during the SARS-CoV-2 epidemics worldwide [6,22]. Although the underlying mechanism leading to the development of the GBS is still unclear, clinical presentation, course, response to treatment, and outcome are similar in SARS-CoV-2-associated GBS and GBS due to other triggers [8]. Symptoms associated with GBS in children are numerous and include weakness, paraesthesia, ataxia, bulbar dysfunction, dysphagia, autonomic dysfunction, changes in consciousness, and respiratory distress [15]. In approximately 15-20% of children with GBS, ineffective breathing pattern leads to respiratory failure and the need for mechanical ventilation [9]. An ineffective breathing pattern was recorded in one child in this study. Therefore, the nurses continuously assessed the child's respiratory status, maintained a clear airway, placed the child in proper body alignment for maximum breathing pattern, taught the child incentive spirometry, and administered oxygen. During nursing care of 3 (21.4%) children, nurses have performed chest percussion, practiced postural drainage techniques, breathing, and coughing exercises. Five (35.7%) children had minor changes in consciousness. As changes in consciousness can occur at any stage of the disease, nurses conducted a continuous quantitative and qualitative assessment of the level of consciousness in 11 (78.6%) children. Impaired physical mobility related to decreased muscle strength and endurance secondary to neuromuscular impairment was reported in all children.



Prolonged immobilization and bed rest affect almost every organ system, especially the musculoskeletal since denervated muscle can lose as much as 95% of its bulk [23]. Therefore, potential problems related to prolonged bed rest, such as the risk for pressure ulcer or the risk for venous thromboembolism, might be often present during nursing care for children with GBS as well as collaborative problems. Although a small number of authors describe bladder dysfunction in children with GBS [15,24], 2 (14,3%) children in this study had impaired urinary elimination; one of them with urinary retention necessitating catheterization. As urinary retention is associated with severe GBS [25], nurses have been performing a continuous assessment of the renal system for early detection of impaired urinary elimination in 12 (85.7%) children. Nursing assessment of a child's gastrointestinal system is especially relevant, while changes in enteral nutrition of children with GBS can cause severe complications such as superior mesenteric artery syndrome [26]. Four (28.6%) children had imbalanced nutrition: less than body requirements, 2 (14.3%) of which suffered from impaired swallowing that required adaptation and individualization of nursing interventions to meet the nutritional needs of children and prevent aspiration. Three (21.4%) children in this study suffered from diarrhea, which is consistent with other studies [15,27]. This problem requires individualized specific nursing interventions including assessment and regulation of food/fluid intake/elimination, prevention of dehydration, and damage to the skin. Acute pain related to inflammation of the peripheral nerves; inflammation and smooth muscle spasms secondary to gastrointestinal infection; tissue trauma and reflex muscle spasms secondary to diagnostic tests are more common actual nursing diagnoses in children than in adults with GBS [14,28]. The pain was recorded in 13 (92.9%) children in this study, while previous studies have found the incidence of pain varying between 13% and 79% [14]. Unfortunately, sometimes it is difficult to distinguish between hypoesthesia, pain, and paraesthesia. Therefore, the pain in children with GBS often remains unrecognized [14,25]. In contrast, certain studies describe the pain treatment with various analgesics and strong opioids [14,29]. The assessment (quantitative and qualitative) and (non) pharmacological pain management is within the nursing competency, which allows nurses to perform independent and team procedures with the necessary holistic and individualized approach.

Although there are many potential problems in nursing care for children with GBS (e.g., the risk for aspiration, the risk for injury, the risk for falls, etc.), the most common potential problem was the risk for infection, recorded in 11 (78.6%) children. Many invasive diagnostic and therapeutic procedures can be performed during the health care of children with GBS. Consequently, the following nursing diagnosis may often be found: the risk for infection related to a site for organism invasion secondary to intubation [15,27], parenteral nutrition [26], tube feedings [26,27], lumbar puncture [14,16], immunotherapy [16,18], urinary catheterization [24], etc. The analysis also indicates that none of the five potential problems become

an actual problem, which represents the indicator and result of high-quality nursing care. It is evident that potential problems are common in children with GBS. Therefore, preventing the progress of these problems requires a high level of specific knowledge, skills, independence, and responsibility of nurses.

The categorization of the examined children in this study provided an insight into the severity of GBS, indicating increased needs for health care and nurse engagement [12]. Most of the children were in the second and third, and 2 children were in the fourth (heaviest) category. This reflects the unpredictable course and outcome of GBS and imposes the need for complex, holistic, and individualized nursing care for children with GBS, which is a significant professional and personal challenge for nurses.

### Study limitations

There are two major inevitable limitations to this study that should be considered. First, the small number of children in the five-year study period resulted from the usually globally rare incidence of GBS. Given the number of respondents, it was not possible to do complex correlation statistics. Second, due to the lack of similar international studies, it was impossible to make comparisons and richer discussions of those results related to potential problems and categorization of children according to the needs for health care.

### Implications for theory and practice

This study should motivate other researchers to conduct similar studies for international comparison of results and to upgrade general global knowledge on GBS. Also, the results of this study can help nurses and other health professionals in assessment, planning, implementation, and evaluation of health care based on the needs and problems of the child, which ultimately contributes to raising the quality of health care for children with GBS.

## CONCLUSIONS

In the five-year study period, 14 children with GBS were hospitalized in five Croatian hospitals. Most of them were adolescent boys. Almost all children were dependent. Therefore, the highest prevalence of actual problems was related to the children's mobility and self-care activities. The risk for infection was the most common potential problem in the nursing care of children with GBS. In almost all children, nurses performed specific interventions before, during, and after numerous (non)invasive diagnostic procedures and procedures for assessing and treating the children's pain. Half of the examined children belonged to the third and fourth categories requiring extremely demanding, holistic, and individualized nursing care.

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Manuscript received: 09.12.2021

Manuscript accepted: 20.01.2022

Translation: Barbara Kružić/ORATRIX, language services and counseling, Kralja Tomislava 87, 31500 Nasice