Cumhuriyet Medical Journal, 45(2): 21-30, 2023
DOI: http://dx.doi.org/ 10.7197/cmj.1240428

Cumhuriyet Medical Journal

| cmj.cumhuriyet.edu.tr | Founded: 2004 Available online, ISSN:1305-0028 Publisher: Sivas Cumhuriyet Üniversitesi

Emergency Service Perspective of Families with Children Who Have Neurodevelopmental Diseases

Hayri Canbaz[1], Atilla BEŞTEMİR[2], Murat GÜLŞEN[3], Alpay TUNCAR[4]

[1] *Department of Emergency Medicine, University of Yıldırım Beyazıt, Yenimahalle Training and Research Hospital, Ankara/ Turkey*

[2] *Department of Emergency Medicine, University of Health Sciences Faculty of Medicine, Bakırkoy Dr. Sadi Konuk Training and Research Hospital, Istanbul/Turkey*

[3] *Department of Pediatrics, Etlik City Hospital Ankara/Turkey*

[4] *Department of Emergency Medicine, Etlik City Hospital Ankara/Turkey*

**Corresponding author*

Research Article

History

Received: 23/01/2023
Accepted: 09/06/ 2023

ABSTRACT

Background: It is known that children with neurodevelopmental diseases have frequent traumas like falling and apply to emergency department which significantly affects patient and family. Our aim is to examine the families' view and the problems encountered in emergency services by examining their answers to questionnaire.

Methods: This study was designed retrospectively. Patients registered in Department of Autism, Mental Special Needs and Rare Diseases as families with children who have neurodevelopmental diseases included in the study. 324 families' survey with 12 open-ended questions evaluated in terms of distribution and frequencies with descriptive statistical methods.

Results: By analyzing the data obtained the findings of the research were gathered under 12 main themes and 80 sub-themes. 313 (89.9%) were diagnosed with Down Syndrome, 9 (2.5%) with Angelman Syndrome, 7 (2.02%) with intellectual disability, and 5 (1.4%) with Autism. 34.2% of the children were 0-3 years old, 28.7% were 3-6 years old, 20.9% were 6-10 years old. Emergency services were used in "all cases where urgent intervention is required" (70%), and in cases where "an outpatient appointment couldn't made" (10.8%)

Conclusion: It would be beneficial to examine children with neurodevelopmental diseases in an understanding and patient manner, using a plain and understandable language, in a quiet environment in emergency room. To solve these patient's problems, awareness training of healthcare professionals, having separate examination and observation room, ensuring accessibility and arranging the room with necessary medical supplies and equipment should be made

Keywords: Neurodevelopmental Disorder, Emergency Service, Autism, Down Syndrome, Cognitive Developmental Delay

Nörogelişimsel Hastalığı Olan Çocukların Ailelerinin Acil Servis Perspektifi

Süreç

Geliş: 23/01/2023
Kabul: 09/06/ 2023

ÖZ

Amaç: Nörogelişimsel hastalıklara sahip çocukların düşme gibi travmalara sık maruz kaldığı ve acil servise başvurdukları bilinmektedir. Bu başvurular hem hastayı hem de aileyi önemli ölçüde etkilemektedir. Hatta bazı aileler acil servise başvurmaktan çekinmektedirler. Bu çalışmada amacımız, ailelerin anket sorularına verdikleri cevapları inceleyerek acil servis hizmetlerine bakışlarını ve karşılaştıkları sorunları araştırmaktır.

Yöntemler: Bu çalışma retrospektif olarak tasarlanmıştır. Otizm, Zihinsel Özel Gereksinimler ve Nadir Hastalıklar Dairesi Başkanlığında kayıtlı ve nörogelişimsel hastalığı olan çocuklara sahip aileler çalışmaya alındı. 324 ailenin açık uçlu 12 anket sorusuna verdikleri cevaplar incelenip, dağılımı ve frekansları tanımlayıcı istatistiksel yöntemlerle değerlendirildi.

Bulgular: Katılımcıların cevapları incelenerek elde edilen verilerin analiz edilmesiyle araştırmanın bulguları 12 ana tema ve 80 alt tema başlığı altında toplandı. Katılımcıların 313'ü (%89,9) Down Sendromlu, 9'u (%2,5) Angelman Sendromlu, 7'si (%2,02) zihinsel engelli, 5'i (%1,4) Otizm tanılıydı. Çocukların %34,2'si 0-3 yaş, %28,7'si 3-6 yaş, %20,9'u 6-10 yaş aralığındaydı. Acil servislerin %70 oranında "Acil müdahale gereken tüm durumlarda", %10,8 oranında da "poliklinik randevusu alınamadığı durumlarda" kullanıldığı ifade edildi.

Sonuç: Nörogelişimsel hastalıklara sahip çocuklar acil serviste karşılanırken anlayışlı ve sabırlı bir şekilde, sade, anlaşılır bir dil kullanılarak, kalabalık olmayan sessiz ortamda muayenelerinin yapılmasının faydalı olacağı tespit edilmiştir. Sağlık çalışanlarına verilecek farkındalık eğitimi ve fiziksel koşullarda 'Ayrı muayene ve müşahade odası bulunması', 'Erişilebilirlik' ile gerekli tıbbi malzeme ve donanımının nörogelişimsel bozukluğa sahip çocuğa göre gözden geçirilmesinin bu gruptaki hastaların sorunlarını çözeceği düşünülmektedir.

Anahtar sözcükler: Nörogelişimsel Bozukluk, Acil Servis, Otizm, Down Sendromu, Bilişsel Gelişim Geriliği

[1] *dr_endorfin@yahoo.com* https://orcid.org/0000-0001-6989-7854 [2] *attilabes@hotmail.com* https://orcid.org/ 0000-0003-0986-9039
[3] *mgulsen0000@hotmail.com* https://orcid.org/0000-0003-4494-9536 [4] *dralpaytuncar@gmail.com* https://orcid.org/ 0000-0002-3889-819X

How to Cite: Canbaz H,Bestemir A, Gulsen m, Tuncar A (2023) Investigation of COVID-19 Anxiety Levels Of Physicians, Cumhuriyet Medical Journal, June 2023, 45 (2): 21-30

Introduction

Neurodevelopmental diseases are multifaceted conditions with cognitive, communicative, behavioral and motor skill disorders due to abnormal brain development [1,2]. The main ones are Down Syndrome, autism spectrum disorder (ASD), cognitive developmental delay [1-4]. Down Syndrome is a genetic abnormality that occurs as a result of the number of chromosomes in body cells being 47 (trisomy 21) [5]. Down syndrome is one of the leading causes of intellectual disability [6,7]. Various health problems can accompany including learning and memory deficits, congenital heart diseases (CHD), Alzheimer's disease (AD), leukemia, cancers and Hirschprung's disease (HD). It's incidence varies between 1:319 and 1:1000 per live births [6,7]. OSB is a lifelong neurological condition characterized by abnormal behaviors and impairments in communication skills and social interactions [3]. Population prevalence estimates made by the World Health Organization shows that 1:100 children worldwide has ASD [4]. Cognitive developmental delay is another neurodevelopmental disease which defined as a serious delay in two or more areas of motor function, language and speech, cognitive function, playing and social skills in a young child, that can be seen in 1:100 children [1,3].

Children with neurodevelopmental disorders are 30-70% more likely to apply emergency department for any reason [8]. It is known that traumas such as falling, hitting and tripping are common in patients with neurodevelopmental diseases and they apply to the emergency service [9]. This situation creates stress and crisis situations with emergency service workers [8]. Despite these difficulties regarding emergency service applications, 52% of Down syndrome who had respiratory tract disease applied to the emergency department [10]. The mean age of the patients were 7.8 years, and the most common comorbidities were congestive heart failure, dysphagia/difficulty feeding, and asthma [10]. Children with ASD are 20% more likely to apply to the emergency department than their peers without ASD [8]. The injury intervention rate of children with ASD was significantly higher than children without disabilities [8]. Children with ASD had 7.6 times higher application rates for poisoning, 2.5 times higher for upper extremity injuries, 3 times higher for fractures, and higher rates for self-inflicted injuries and suicide [8].

Admission to the emergency department with a psychiatric problem is 9 times higher [11] and it is one of the most problematic area of health services in the world for families [12,13]. Visual and auditory stimuli that distract attention can cause children with neurodevelopmental disorders to be confused, distressed and even be fearful and anxious [14]. Staff moving too fast can overwhelm a child and even the seemingly simple act of entering a crowded, noisy waiting room can trigger problematic behavior [14]. This sensory overload and anxiety may cause the child to become aggressive towards hospital personnel, to equipment or self [14].

All these applications have a significant impact on both the patient and family. Some families even hesitate to go to the emergency room. There are not many articles about the expectations of families from emergency services and how important these expectations are for them. Evaluation of this issue from a broad perspective with using scientific data will shed light on what precautions to take.

In this study, our aim is to examine the answers given to the questionnaire by the participating families with children who have neurodevelopmental disorders and to investigate their perspective on emergency services and the problems they encountered.

Materials and methods

This study was designed in a non-interventional, retrospective descriptive observational manner and conducted between June and December 2021. Questionnaire form (Appendix-1) and voluntary participation form (Appendix-2) developed by the researcher were used in the study.

The answers to the open-ended questionnaires prepared in the light of scientific data were evaluated by examining the answers of 324 families who have children with neurodevelopmental diseases which were registered in the Department of Autism, Mental Special Needs and Rare Diseases. 54 of families were excluded from the study because they did not want to participate or could not complete the questionnaire.

Data were collected from survey questions using qualitative research methods. The distribution of the data was evaluated using descriptive statistical methods using the SPSS program.

Results

After analyzing the data, the findings of the research were gathered under 12 main themes and 80 sub-themes. The frequency and percentage distributions of the participants' responses to this theme and its sub-themes are given in Table 1-7.

When 'What are the Neurodevelopmental Diseases of the Child?' theme was examined, it was found that 89.9% (n=313) had Down syndrome, 2.5% (n=9) Angelman syndrome, 2.0% (n=7) had intellectual disability and 1.41% (n=5) of them had Autism (Table 1). 34,26% of these children were 0-3 years old, 28,70% were 3-6 years old, 20,98% were 6-10 years old (Table 2).

In response to the question in which situations families use the emergency services of hospitals, %70 answered 'In all cases where emergency intervention is required', while 10.8% answered "when couldn't get an outpatient appointment. The least response was 'to prescribe medication' (Table 3). When the positive aspects of emergency services were investigated, it was reported most frequently '24-hour uninterrupted service' with a rate of 61.25% (Table 4). When the problems faced in the emergency services asked, the most common answers were 'Inadequate examination' with a frequency of 34.4% (n=165) and 'Connecting all the disorders of the child to special needs' with a frequency of 21.50% (n=103). Lack of knowledge and experience had a very low frequency of 1.25% (n=6) (Table 5). The patients in our research group were greeted most frequently by 'Medical Secretaries' with 63.8% (n=69) and security personnel the least with a rate of 0.9% (n=1) in the emergency department (Table 6).

In the process of receiving emergency service, when the theme of the health personnel having enough information about the special needs of the child with neurodevelopmental disease was investigated, it was seen that 57.1% (n=185) of families replied negatively and only 9.6% (n=31) replied positively. When their children needed an intervention, 37.6% (n=191) of families wanted an approach with "understanding and patience", 22.4% (n=114) of them wanted a "plain and understandable language", %20.1 (n=102) of them needed "a quiet and environment without a crowd" and 18.5% (n=94) of them wanted "a support personnel next to a health personnel" (Table 7).

When asked about which specialties needed to be present in the emergency room in order for these children to benefit from the emergency service better, answers were 24.3% (n=218) doctor, 17.2% (n=155) nurse, 16.9% (n=152) psychologist, 20.8% (n=187) child development specialist and 9% (n=81) social worker.

When parents asked who should be educated to provide better approach to these children in emergency services, they replied 24.7% (n=217) doctors, 23.9% (n=210) nurses, 0.9% (n=8) health workers and %0.2 (n=2) of them thought current education is sufficient.

When families asked about which physical conditions necessary to provide better service to these children in emergency services, 31.5% (n=305) replied "Availability of separate examination and observation room", 26.8% (n=259) "Accessibility" and 21.4% (n=207) "medical equipment and equipment should be developed".

Families thought that they were not sufficiently informed about their current health problem after completing emergency services, with a rate of 67.6% (n= 219).

Table 1

What are Child's Neurodevelopmental Diseases?

Main Theme	Sub-Themes	n	%
Neurodevelopmental Disease of Child	Down syndrome	313	89,94
	Heart Disease	1	0,29
	Renal Disease	1	0,29
	Epilepsy	1	0,29
	Angelman Syndrome	9	2,59
	Cerebral Palsy	2	0,58
	Visually Impaired	4	1,15
	Mentally Disabled	7	2,02
	Autism	5	1,41
	Muscle Diseases	2	0,58
	Hearing Impaired	2	0,57
	1p36 deletion genetic syndrome	1	0,29
Total		348	100

Table 2

What age group is your patient in?

Main Theme	Sub-Themes	n	%
Patient's age group range	0-3	111	34,26
	3-6	93	28.70
	6-10	68	20,98
	10-15	33	10.19
	15-18	19	5,87
Total		324	100

Table 3

In which situations do you use the emergency services of hospitals?

Main Theme	Sub-Themes	n	%
Situations in which Emergency Services are used	In all cases where emergency intervention is required	227	70.0
	In emergencies related to chronic diseases	58	17,7
	Injury and accidents	3	0,93
	When you can't get an outpatient appointment	35	10,8
	To Prescribe medication	1	0,31
Total		324	100

Table 4

What are the positive aspects of hospital emergency services?

Main Theme	Sub-Themes	n	%
Positive aspects of emergency services	24 hours uninterrupted service	254	61,65
	Short waiting time	49	11,90
	Quick response	82	19,90
	Smiling personnel	20	4,85
	Obligation	3	0,73
	Nothing	4	0,97
Total		412	100

Table 5

What are the problems encountered in the emergency services of hospitals?

Main Theme	Sub-Themes	n	%
Problems encountered in emergency services	Not informed adequately	88	18,37
	Linking all of the child's ailments to his/her special needs	103	21,50
	Health personnel not being emphatetic enough	55	11,48
	Inadequate physical examination	165	34,44
	Ill treatment	10	2,08
	Crowdedness	18	3,75
	No order of priority	6	1,25
	No children's department	8	1,67
	Very well taken care of	18	3,75
	Lack of knowledge and experience	6	1,25
	Referring to routine follow up clinic	2	0,41
Total		479	100

Table 6

Which health personnel contact you first when you go to the emergency services of hospitals?

Main Theme	Sub-Themes	n	%
First contact health personnel in emergency rooms	Doctor	19	17,6
	Nurse	15	13,9
	Medical Secretary	69	63,8
	Nurse asistant	2	1,9
	Security personnel	1	0,9
	No one	2	1,9
Total		108	100

Table 7

How would you like your child to be contacted when an intervention is needed in the emergency departments of hospitals?

Main Theme	Sub-Themes	n	%
How would you like your child to be contacted?	Simple, understandable language	114	22,48
	Be understanding and patient	191	37,67
	Having support personnel with healthcare personnel	94	18,54
	In a quiet, uncrowded environment		
	Smiling face	102	20,11
	Well taken care of	4	0,78
		1	0,19
	Having communication together with parents	1	0,19
Total		507	100

Discussion

In our study, in which we aimed to investigate the perspective of families who have neurodevelopmental diseases about emergency services and problems they encountered, the majority who answered the survey questions were those with Down syndrome (89%). Other groups include children with mental retardation (2.5%), autism spectrum disorder (1.4%) and Angelman syndrome (2%). Angelman syndrome is a severe developmental and neurobehavioral disorder characterized by impaired speech and movement/balance, frequent and inappropriate laughter, a happy affect, an easily excitable unique personality and four basic features [15-18].

Yale New Haven Hospital has official policies regarding the use of restraints on children in emergency departments, but individual decisions regarding patients with neurodevelopmental diseases are very difficult and specific [19]. Restriction rate was 6.8% in emergency services [13]. The restraint or immobilization method, which is commonly used for young people, can also be applied to children when pharmacological intervention cannot be performed [20,21]. However, the result of this application may be more frightening for the patient and may exacerbate the situation [20,21]. In our study; it was determined that there should be 152 (16.9%) psychologists and 187 (20.8%) child development specialists should be present to get better service in emergency department. From the data obtained from the answers of the participating families, it was seen that the restriction and the presence of a security guard were not mentioned. This situation made us think that there is an objective family view and approach that focuses on the quality of service.

The child with neurodevelopmental disease should not be behaved in a condescending way, listen them carefully, cooperate at the same time, and the language used should be clear, simple and understandable [22]. The intonation, speed and accent of the speech are also important [23]. The posture, proximity, orientation, bodily contact and gaze of the personnel, as well as the expression of the face and gestures are also important as nonverbal communication [22,24]. On the other hand, it should be kept in mind that patients may avoid eye contact and make different gestures to express themselves with their behaviors [25]. Health personnel should act without prejudice and away from misinterpretations. Because preconceived ideas and stereotypes have been reported to be an obstacle for appropriate approach and treatment for children with neurodevelopmental diseases [26]. Therefore, preventive and supportive studies are needed to alleviate the burden and stress for those patients [12]. Since these children have mental health and behavioral problems, they need to be appeased [13]. In our study, when children needed intervention, 37.6% (n=191) of the families wanted an insightful and patient approach, 22.4% (n=114) wanted simple and comprehensible language usage, 20.1% (n =102) wanted to be in a quiet environment without a crowd and 18.5% (n=94) wanted to have support personnel next to the healthcare professional (Table 7). It is recommended to conduct communication trainings for example, Çınar O. et al found this training was beneficial [27].

When families were asked which situations they used the emergency service, they replied “In all cases where urgent intervention is required" with the rate of 70% and unlike our study, Kalb et al

reported that admissions due to psychiatric problems were more frequent [11]. In another study, it was reported that physical or verbal aggression was seen in 54%, emergency situations and injuries were observed in 23% [12].

Emergency department physicians may confuse social, cognitive and psychiatric symptoms with psychosis [11]. It has been stated that these are the findings of the child's main diagnosis and do not reflect the true comorbidity rates and that the emergency room physicians are inadequate in children with neurodevelopmental diseases [11]. In our study, results supporting this issue were obtained. When asked whether the health personnel have sufficient knowledge about the special needs of the child with neurodevelopmental disease during the process of receiving emergency service, 57.1% (185) of the families replied negatively and 9.6% (31) positively. In addition, when asked which specialists should receive training regarding in this subject, 24.7% (217) replied as doctors, 23.9% (210) as nurses, 0.9% (8) as all health workers. 0.2% (2) of the participating families stated that the education was sufficient. 'All health workers' defined as 'All health workers who communicate with patient until they reach doctor'. When the problems faced by families with children with neurodevelopmental disorders were investigated in the emergency services, the answer was 'Inadequate examination' with a frequency of 165 (34.4%) and 'Connecting all the disorders of the child to special needs' with a frequency of 103 (21.5%) mostly (Table 5). The inadequacy of knowledge and experience stands out in the results, even though it has a very low frequency of 6 (1.25%). Likewise, Tint and et al reported that a patient was transferred to the emergency service of another center due to insufficient examination and lack of experience in the center where he first applied [12]. In addition, it is necessary for health personnel and emergency physicians to understand that it may require more time for the appropriate evaluation of the patient [28].

There may be great difficulty in keeping individuals with neurodevelopmental diseases in the emergency room [13]. In the studies of Bradley and Lofchy (2005) and Vaz (2010), it was stated that various physical arrangements can be made for patients to reduce the stress levels when they apply to emergency services and have examinations [28,29]. Similarly in our study, when families asked which physical conditions are needed in emergency services; 31.5% (n=305) replied as to have separate examination and observation room, 26.8% (n=259) to be accessible and 21.4% (n=207) to have advanced medical equipment. Additionally, examination room lights should be dimmed to have minimal sensory stimulation likewise cloths should be used instead of paper gowns or drapes [29].

It has been mentioned that children with neurodevelopmental diseases should be prioritized according to the emergency situation and the importance of nurses' decision making in triage evaluations [30]. In our study, patients were most frequently met by Medical Secretaries (63.8%) when entering the emergency department, and 17.6% doctors and 13.9% nurses follows that and security personnel is the least one with a rate of 0.9% (1) (Table 6). When these results are reviewed, it is considered that it would be better for patients to be met by a experienced nurse. Comfortable rooms and positions, nurse-focused triage protocols, using distracting activities, and application of restrictions when necessary are recommended for pain assessment and rapid initiation of treatment [31]. Because symptoms such as dullness, trembling, paleness, sweating, sharp breath and breath-holding, seeking comfort or physical closeness; reported as common symptoms for pain in the population of children with cognitive impairment [32]. In addition, changes in breathing pattern, sudden movements and verbal outbursts can also be seen [33]. Children with Down syndrome may have difficulties or delays in determining the expression and location of pain [34,35]. Children with autism spectrum disorder, on the other hand have a slower response to recovery [36,37]. Since there may be fear and anxiety in families, they should be prepared by informing them before the examination and procedures [38,39]. Similarly in our study, families thought that they didn’t received enough information and guidance about their current health problem after discharging from emergency services (67.6%).

Parents can be active participants in helping emergency physicians by keeping their child busy with interesting activities and make them cope with procedures [33]. The changes in the facial expressions of the patients should be observed and their attention should be distracted from the examination or procedure. Language-based coping skills such as encouragement and praise can be used [40,41]. Assigning tasks to parents also acts as a distraction for them and possibly reduce their personal anxiety [40].

Despite all these opinions, the positive aspects of emergency services in our study were that 24-hour uninterrupted service (61.25%) and rapid intervention (19.9%). In another study, it was stated that the number of emergency service personnel who intervene in this group of children should be specially planned and limited [29].

Limitation

Our study is in the form of a qualitative, descriptive preliminary study. Our study based on a voluntarily participated survey. Therefore, the status of the entire population couldn't be determined more clearly. The strength of our study is its large sample size and its ability to provide national estimates.

Conclusion

It has been determined that when children with neurodevelopmental diseases are welcomed in the emergency room, it would be beneficial to communicate with the health personnel in a quiet and non-crowded environment, by using a simple and understandable language, in an understanding and patient manner, by having support personnel next to the health personnel, and to be examined in a sufficient time about their special needs and emergency ailments.

It is thought that an awareness training given to healthcare professionals about using a separate examination and observation room, being accessible and reviewing the necessary medical supplies and equipment for a child with neurodevelopmental disorder will mostly solve the problems of these patient group.

References

1. Harris, James C, New classification for neurodevelopmental disorders in DSM-5. Current Opinion in Psychiatry: March 2014 - Volume 27 - Issue 2 - p 95-97. doi: 10.1097/YCO.0000000000000042.

2. Heady N, Watkins A, John A, Hutchings H. Prevalence of neurodevelopmental disorders and their impact on the health and social well-being among looked after children (LAC): a systematic review protocol. Syst Rev. 2022 Mar 19;11(1):49. doi:10.1186/s13643-022-01923-6.

3. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM–5) Washington DC: American Psychiatry Association; 2013.

4. WHO. World Health Organisation. Autism Spectrum Disorders. 2022. Available from: https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

5. Cooley, C. Down Sendromu (Çev: Emine Pürçüklü). Murat Yurdakök (Editör). Pediatri içinde. Ankara: Güneş Kitabevi; 2007

6. O'Nualláin S, Flanagan O, Raffat I, Avalos G, Dineen B. The prevalence of Down syndrome in County Galway. Ir Med J. 2007 Jan;100(1):329-31. PMID: 17380922. https://pubmed.ncbi.nlm.nih.gov/17380922/

7. Canfield MA, Honein MA, Yuskiv N, Xing J, Mai CT, Collins JS, et al. National estimates and race/ethnic-specific variation of selected birth defects in the United States, 1999-2001. Birth Defects Res A Clin Mol Teratol. 2006 Nov;76(11):747-56. doi: 10.1002/bdra.20294. PMID: 17051527.

8. McDermott S, Zhou L, Mann J. Injury treatment among children with autism or pervasive developmental disorder. J Autism Dev Disord. 2008 Apr;38(4):626-33. doi: 10.1007/s10803-007-0426-9. Epub 2007 Aug 10. PMID: 17690968.

9. Rose L, McKim D, Leasa D, Nonoyama M, Tandon A, Bai YQ, et al. Patterns of healthcare utilisation for respiratory complications of adults with neuromuscular disease: a population study. Eur Respir J. 2018 Sep 18;52(3):1800754. doi: 10.1183/13993003.00754-2018. PMID: 30139772.

10. Blake JM, Estrada Gomez D, Skotko BG, Torres A, Santoro SL. Pneumonia and respiratory infection in Down syndrome: A 10-year cohort analysis of inpatient and outpatient encounters across the lifespan. Am J Med Genet A. 2021 Oct;185(10):2878-2887. doi: 10.1002/ajmg.a.62355. Epub 2021 May 31. PMID: 34056836.

11. Kalb LG, Stuart EA, Freedman B, Zablotsky B, Vasa R. Psychiatric-related emergency department visits among children with an autism spectrum disorder. Pediatr Emerg Care. 2012 Dec;28(12):1269-76. doi: 10.1097/PEC.0b013e3182767d96. PMID: 23187983.

12. Tint, A, Robinson, S, & Lunsky, Y (2011). Emergency Department Assessment and Outcomes in Individuals with Autism Spectrum Disorders. Journal on Developmental Disabilities, 17(2), 56-59. Available from: https://oadd.org/wp-content/uploads/2011/01/41010_JoDD_17-2_56-59_Tint_et_al.pdf

13. Dorfman, D. H., & Mehta, S. D. (2006). Restraint Use for Psychiatric Patients in the Pediatric Emergency Department. Pediatric Emergency Care, 22(1), 7-12. doi: 10.1097/01.pec.0000195758.12447.69. PMID: 16418605

14. Giarelli, E, Gardner, MR. Nursing of autism spectrum disorder: evidence-based integrated care across the lifespan. Springer Publishing Company, 2012.

15. Williams CA, Angelman H, Clayton-Smith J, Driscoll DJ, Hendrickson JE, Knoll JH, et al. Angelman syndrome: consensus for diagnostic criteria. Angelman Syndrome Foundation. Am J Med Genet. 1995 Mar 27;56(2):237-8. doi: 10.1002/ajmg.1320560224. PMID: 7625452.
16. Willlams CA. Lossie AC. Driscoll Dl. Angelman syndrome. Gene Clinics 1998; Avail- able at URL: wrnv.geneclinics.org.
17. Glenn CC, DriscoU Dl. Yang TP. Nicholls RD. Genomic ~mprinting: Potential func- tion and mechanisms revealed by the Prader Willi and Angelman syndromes. Afol Hum Reprod 1997:3:321-332.
https://doi.org/10.1093/molehr/3.4.321
18. Kishino T, Lalande M, Wagstaff J. UBE3A/E6-AP mutations cause Angelman syndrome. Nat Genet. 1997 Jan;15(1):70-3. doi: 10.1038/ng0197-70. PMID: 8988171.
19. Medical Staff Education. Use of Restraints: Yale-New Haven Hospital. https://www.ynhh.org/-/media/Files/YNHHS/PDF/med-staff-admin/2020-10-27-Revised-Med-Staff-Education.ashx
20. Frank NC, Blount RL, Smith AJ, Manimala MR, Martin JK. Parent and staff behavior, previous child medical experience, and maternal anxiety as they relate to child procedural distress and coping. J Pediatr Psychol. 1995 Jun;20(3):277-89. doi: 10.1093/jpepsy/20.3.277. PMID: 7595816.
21. LeDoux JE. Emotion circuits in the brain. Annu Rev Neurosci. 2000;23:155-84. doi: 10.1146/annurev.neuro.23.1.155. PMID: 10845062.
22. Houghton BM. Caring for people with Down syndrome in A&E. Emerg Nurse. 2001 May;9(2):24-7. doi: 10.7748/en2001.05.9.2.24.c1358.
23. Quinn F. The Principles and Practice of Nurse Education. London, Chapman and Hall, 1997.
24. Argyle M. The Psychology of Interpersonal Behaviour. Harmondsworth, Penguin Publishing Co, 1983.
25. Southampton Community NHS Health Services Trust. Learning Disabilities Resource Package. Proposal Pack. 1999.
26. Shanley E, Guest C. Stigmatisation of people with learning disabilities in general hospitals. Br J Nurs. 1995 Jul 13-26;4(13):759-61. doi: 10.12968/bjon.1995.4.13.759. PMID: 7655262.
27. Cinar O, Ak M, Sutcigil L, Congologlu ED, Canbaz H, Kilic E, et al. Communication skills training for emergency medicine residents. Eur J Emerg Med. 2012 Feb;19(1):9-13. doi: 10.1097/MEJ.0b013e328346d56d. PMID: 22241063.
28. Bradley E, Lofchy J. Learning disability in the accident and emergency department. Advances in Psychiatric Treatment, 2005;11, 345–357 https://doi.org/10.1192/apt.11.1.45
29. Vaz I. Improving the management of children with learning disability and autism spectrum disorder when they attend hospital. Child Care Health Dev. 2010 Nov;36(6):753-5. doi: 10.1111/j.1365-2214.2010.01144.x. PMID: 21039752.
30. Cioffi J. Decision making by emergency nurses in triage assessments. Accident and emergency nursing, 1998, 6.4: 184-191. https://doi.org/10.1016/S0965-2302(98)90077-7
31. Taylor SE, Taylor DM, Jao K, Goh S, Ward M. Nurse-initiated analgesia pathway for paediatric patients in the emergency department: a clinical intervention trial. Emerg Med Australas 2013; 25: 316–23. https://doi.org/10.1111/1742-6723.12103
32. Hennequin M, Morin C, Feine JS. Pain expression and stimulus localisation in individuals with Down's syndrome. Lancet 2000; 356: 1882–87. https://doi.org/10.1016/S0140-6736(00)03259-1
33. Krauss BS, Calligaris L, Green SM, Barbi E. Current concepts in management of pain in children in the emergency department. Lancet. 2016 Jan 2;387(10013):83-92.
https://doi.org/10.1016/S0140-6736(14)61686-X
34. Mafrica F, Schifilliti D, Fodale V. Pain in Down's syndrome. ScientificWorldJournal. 2006 Jan 26;6:140-7. doi: 10.1100/tsw2006.27. PMID: 16493518; PMCID: PMC5917383.
35. Rattaz C, Dubois A, Michelon C, Viellard M, Poinso F, Baghdadli A. How do children with autism spectrum disorders express pain? A comparison with developmentally delayed and typically developing children. Pain. 2013 Oct;154(10):2007-2013. doi: 10.1016/j.pain.2013.06.011. PMID: 24040973.
36. Nader R, Oberlander TF, Chambers CT, Craig KD. Expression of pain in children with autism. Clin J Pain 2004; 20: 88–97. https://journals.lww.com/clinicalpain/Abstract/2004/03000/Expression_of_Pain_in_Children_With_Autism.5.aspx
37. Zelter LK. Krane EJ Pediatric pain management. In: Kliegeman RM, Stanton BF, St Geme JW III, Schor NF, Behrman RE. Nelson textbook of pediatrics, 19th ed. Philadelphia: Elsevier, 2011
38. Tsao JC, Evans S, Seidman LC, Zeltzer LK. Experimental pain responses in children with chronic pain and in healthy children: how do they diff er? Pain Res Manag 2012; 17: 103–09. https://doi.org/10.1155/2012/592108
39. Porter FL, Grunau RE, Anand KJ. Long-term effects of pain in infants, In: Oxford Textbook of Pediatric Pain, 2nd ed, Oxford University Press; 2021; p. 38-45.

40. Cohen LL. Behavioral approaches to anxiety and pain management for pediatric venous access. Pediatrics 2008; 122 (suppl 3): S134–39. https://doi.org/10.1542/peds.2008-1055f
41. Kuttner L. A child in pain. Wales: Crown House Publishing; 2010.