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CHILD/YOUNG WITH EPILEPSY: SCHOOL HEALTH NURSE COMPETENCES INTEGRATIVE REVIEW

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ABSTRACT

Child/youth care with epilepsy is built by a partnership between those around it, throughout the vital system. Promoting health in the school environment contributes to improving the quality of life and the learning process. The school health nurse can play a pivotal role in this process. To achieve full quality of care, you must have valuable support tools as well as specialized skills.

Objective: To identify in the scientific literature studies that divulge the role of the school health nurse in the care of the child/youth with epilepsy.

Methods: Integrative review through research in B-On, Lillacs and Medline. Including studies that addressed nursing care, in school health, to the child/youth with epilepsy. (Identified 42 and selected 9).

Results: The studies identified intervention strategies/competencies of the school health nurse in promoting the health of the child/young person with epilepsy.

Conclusions: The school health nurse, in the care of the child/youth with epilepsy, should involve the family and the school community, in articulation with the health team. The use of tools such as an individual health plan allows everyone to communicate in a common language, intervening biologically and psychosocially.

Keywords: Children; epilepsy; school e education; nursing.

INTRODUCTION

Epilepsy is a disorder of the brain characterized predominantly by recurrent and unpredictable disruptions of its normal function, called epileptic seizures. Epilepsy is not a singular entity of the disease, but rather a variety of disorders that reflect the underlying brain dysfunction and which results from many different causes⁽¹⁾.

The World Health Organization states that approximately 50 million people worldwide suffer from epilepsy, with 2.4 million cases registered each year⁽²⁾.

Epilepsy is the most common neurological pathology in childhood. It also represents one of the main causes of chronic disease in paediatric age^(3,4). According to the American Academy of Paediatrics, it affects 0.5% to 1% of children⁽⁵⁾. It is estimated that one in every 100 children has or will develop this disorder⁽³⁾.

As a chronic pathology, epilepsy is a diagnosis consistently associated to multiple special health needs. This is due to the pathology itself and to its cause(s) or consequence(s), which may compromise the function and/or structure of the body and limit the normal development of the child/youth⁽⁶⁾.

According to the national school health program (2015), "contributing to a suitable response to special health needs, rather than a school health goal, is a movement for children's rights, for the acceptance of difference, the promotion of attitudes of respect, of recognition of personal value and merit"⁽⁷⁾.

The program assumes that children/youth with special health needs, in a school context, will have an individual health plan that meets all the identified needs. This health plan "assesses the impact of health conditions on functionality (activities and participation) and identifies the health measures to be implemented (health needs, therapeutic and rehabilitation measures, among others) to improve school performance, taking into account the environmental factors, facilitators or hinderers, of the school context"⁽⁷⁾.

The individual health plan is the result of a commitment between several participants and it should be built in articulation with the resources of the health services, involving one element from the education and training establishment and the parent or guardian^(7,8).

The health team, and particularly, the school health nurse, should be involved in this cooperation, along with the family and the school, to achieve a common goal: the child/youth's well-being. He/she should see the parents' knowledge as a necessary and supportive action to promote the child/youth's adaptation to his/her condition. The evaluation and revision of the plan should be programmed together⁽⁸⁾.

School is a major context in which the child/youth develops self-concept and understands his/her place in the relationship with his/her peers. A significant part of his/her life is spent in school institutions. Therefore, their role should not be overlooked in their lives, and it is a critical task for children to have a successful participation in this context⁽⁹⁾.

It is of the utmost importance that the epileptic child/youth maintains an active and successful school life. For this to happen, it is indispensable to create an environment leading to his/her participation. So, the partnership between teachers, parents and school health nurses is a fundamental pillar for the construction of his/her school process⁽⁸⁾.

Some studies suggest that a substantial proportion of teachers lacks knowledge on epilepsy and feels somewhat fearful of teaching students with this pathology^(10,11).

Uncontrolled seizures and the possible side effects of medication may potentially disrupt children's cognitive, social and emotional development, leading to a poorer school performance, with attention, concentration, memory and communication difficulties. Sometimes, they may even lead to the need for school absenteeism^(8,13).

Alongside the family, teachers can be active and valuable in monitoring a student's potential side effects, therapy, or seizure activity. They can identify perceptible changes in student's behaviour, emotions, intellectual ability or convulsive activity^(13,14).

Although epilepsy may sometimes be understood as synonymous with cognitive impairment, many epileptics may present a normal or even above average cognitive functioning, a fact that is sometimes not understood but generalized⁽¹³⁾.

Besides suffering from the health problem, children/youth with epilepsy and their families end up dealing also with stigma and discrimination by the school community and with the overprotection of parents and teachers^(3,12,24).

Studies show that the implications of epilepsy-related stigma are extensive, affecting different domains of child/youth and their parents lives, including self-esteem, self-perception, social identity, mood, and mental health. These findings suggest that it is important to identify the factors associated with stigma perception, in order to develop interventions that may reduce this perception^(2,12).

In order to understand the impact of epilepsy on the child/youth's life, the nurse must evaluate not only its biological influences (cause, diagnosis, drug treatment, among others) but also psychosocial ones (family and school relationships, beliefs, behaviour)⁽⁹⁾. The nurse is in a privileged position to maintain the rendering of care to a child/youth and family care, intervening in order to fight stigma, as well as all the factors associated with the disease, that condition their life and act as a barrier to achieve a quality of life as close as possible to that of the healthy child/youth.

According to the above, there is a need for more accessible and updated information about epilepsy in the school context, through a nursing intervention which is continuous and closer to the student, as well as to those around him. We advocate the need to rethink the skills of the school health nurse, essential for the performance of the care given to a child/youth with epilepsy, in an effective partnership with parents/health professionals/school community, as this is a domain of care that requires investment, especially in the area of specialized nursing intervention. In this sense, the objective of this literature review consisted of gathering updated and pertinent scientific evidence on the skills of the school health nurse in the care of the child/youth with epilepsy.

METHODOLOGY

In this process of scientific investigation, which gathered relevant studies on the formulated question, one seeks to systematize the current knowledge. Therefore, the skills of the specialist nurse in children's health and paediatrics, in the scope of school health, will be described specifying intervention strategies in the care to the child/youth. One intends to involve the peers, teachers/staff as well as the family, in order to promote the quality of life of the child/youth in this context.

Research Strategies

At this level of research, the literature databases used to identify the studies will be described. The selection criteria will be evidenced, taking into account methodologies of critical evaluation (according to levels of evidence) and the means of evaluation of the methodological quality will be described, with the purpose of carrying out a critical and comprehensive review of literature.

Following the methodological design of Joanna Briggs Institute (JBI)⁽⁴⁵⁾ and according to the Patient/Problem, Intervention, Comparison, Outcome, Design (PICOD) model, we start with the research question "What are the skills of the School Health Nurse in the Care to the Child/Youth with Epilepsy?"

Table 1 - Levels of evidence JBI.

Patient/Problem	Child/Youth with Epilepsy
Intervention	Skills of the School Health Nurse
Comparison	(Not applied)
Outcome	Care rendered to the Child/Youth
Design	Descriptive Study, under the form of Literature Systematic Review

The systematic research of literature was performed resorting to electronic databases: B-On, Medline and Lilacs, by integrating the following descriptors of the “DeCS: *Children, Epilepsy, School and Education, Nursing*, with the “Boolean” operator “AND”. The following inclusion criteria were considered: original research articles, in all languages, published in the period between January 2013 and May 2018, with a full text and which approached the researched topic, either in the title or in the abstract. The “full text” and “reviewed by specialists” limiters were used. The research was carried out in the period between April 26th and May 15th, 2018.

Selection Criteria

The selection of articles was progressively phased. According to the research results (figure 1), 42 studies were identified. A filtration was performed and the duplicate articles (8) were removed, thus leaving 34 studies. In a second stage, after reading and evaluating titles and abstracts, 24 articles were excluded, since they did not fit the objectives of the review and did not answer the departure question. So, only 10 articles remained at this stage. In the next phase, the Joanna Briggs Institute's Critical Assessment Checklist (JBI)^(15,16) was applied to all articles. In this critical evaluation, articles with more than 50% of “YES” responses were included, having excluded an article that did not fulfil these criteria, which corresponded to including only 9 articles in this stage.

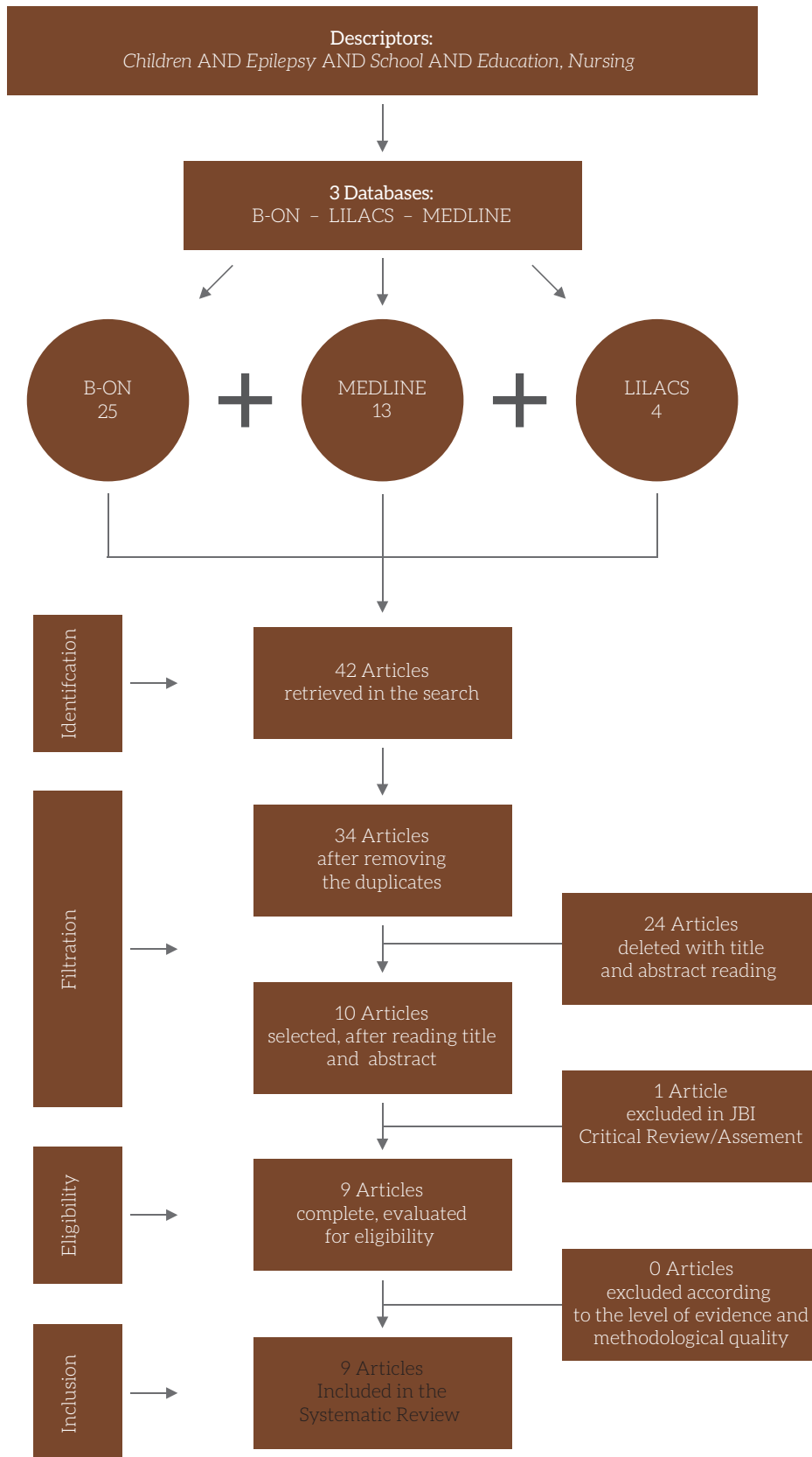


Figure 1 – Prisma 2009 Flow Diagram.

Source: Manual 2015 JBI⁽¹⁵⁾.

In the continuity of the process of evaluation of the studies, they were submitted to a verification stage and classified, according to the levels of evidence. They are found and displayed hierarchically in the following figure and table, based on the *Joanna Briggs Institute (JBI)*⁽¹⁷⁾.

Table 2 – Levels of evidence JBI.

	Article	Author (Year)	Level of Evidence	Study Design
A1 ⁽²³⁾	<i>Perceptions of patient education during hospital visit – described by school-age children with a chronic illness and their parents</i>	Marjatta Kelo Elina Eriksson; Ilse Eriksson (2013)	Level 4.c	Observational-descriptive study Case Series
A2 ⁽²²⁾	<i>Chronic Neurological Conditions In the Classroom: A School Nurse Curriculum For Sustaining a Healthy Learner</i>	Julie M. Sprague-McRae; Ruth K. Rosenblum (2013)	Level 5.b	Expert opinion and research bank Consensus of Experts
A3 ⁽²⁰⁾	<i>The effect of a modular education program for children with epilepsy and their parents on disease management</i>	Fatma D. T. Gürhopur; Ayşegül I. Dalgıç (2018)	Level 1.c	Experimental draw RCT (Controlled and Randomized Test)
A4 ⁽⁸⁾	<i>Increasing Epilepsy Awareness in Schools: A Seizure Smart Schools Project</i>	Heather A. Brook; Cynthia M. Hiltz; Vicki L. Kopplin; Linda L. Lindeke (2015)	Level 2.d	Quasi-experimental design Pre-test
A5 ⁽²¹⁾	<i>Ethical Issues in School Nursing</i>	Teresa Savage (2017)	Level 5.a	Expert opinion and research bank Systematic review of expert opinion
A6 ⁽¹¹⁾	<i>Effectiveness of Video Assisted Teaching Programme on Epilepsy in Children among the Primary School Teachers in the Selected Schools of Udipi District</i>	Pillai N. Balakrishna; Anjalin D'Souza; Nidhin Tomas (2016)	Level 2.d	Quasi-experimental design Pre-test
A7 ⁽¹³⁾	<i>Challenges of epileptic learners as viewed by educators in rural schools in Limpopo Province, South Africa</i>	N.N. Nefolovho; N.J. Ramakuela; D.U. Ramathuba (2015)	Level 4.c	Observational-descriptive study Case Series
A8 ⁽²⁴⁾	<i>A model for internalized stigma in children and adolescents with epilepsy</i>	Joan K. Austin; Susan M. Perkins; David W. Dunn (2014)	Level 4.c	Observational-descriptive study Case Series
A9 ⁽¹²⁾	<i>The stigma experiences and perceptions of families living with epilepsy: Implications for epilepsy-related communication within and external to the family unit</i>	Ailbhe Benson; Stephanie O'Toole; Veronica Lambert; Pamela Gallagher; Amre Shahwan; Joan K. Austin (2016)	Level 4.c + 4.b	Cross-sectional observational study + Case Series

Source: New JBI Levels of Evidence⁽¹⁸⁾.

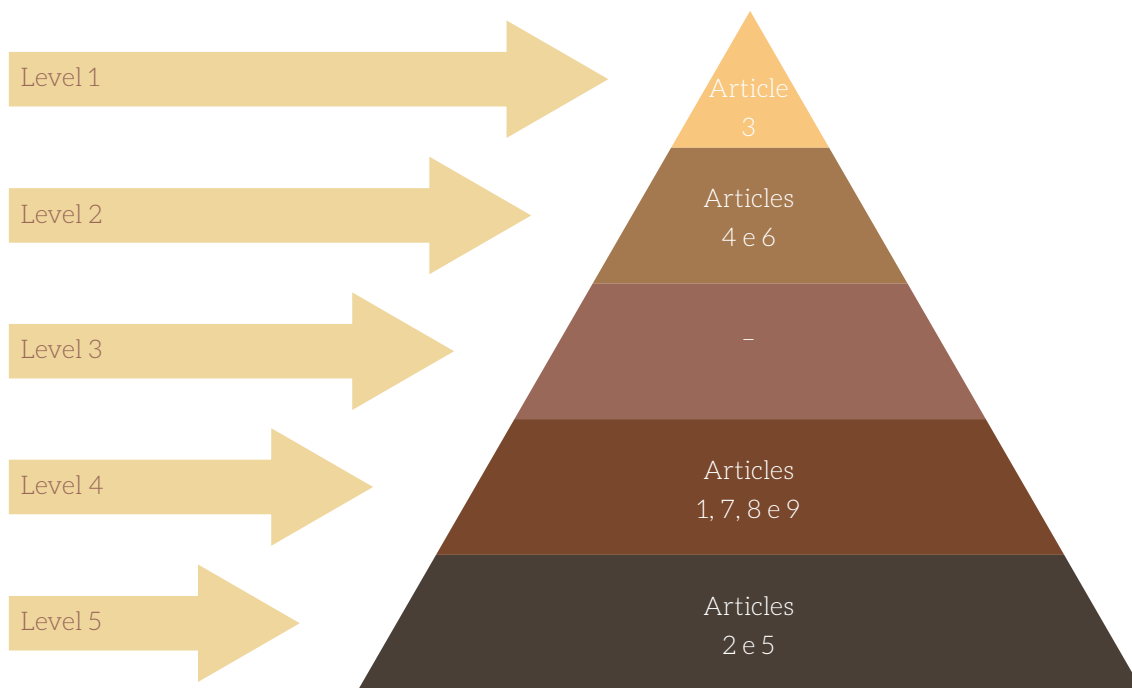


Figure 2 - Hierarchically arranged levels of JBI evidence.

With respect to the effectiveness of the studies, a heterogeneity of designs could be verified. However, at this stage, studies were not excluded, due to the interest of the contents addressed and to their contribution for the construction of answers to the departure question.

In the next phase of the process of studies selection, one proceeded to the evaluation of the methodological quality of the quantitative studies, measured by the *Quality Assessment Tool of the Effective Public Health Practice Project (EPHPP)*⁽¹⁸⁾, all of which were evaluated to have a high methodological quality. So, they have been included.

Table 3 - Evaluation of the Methodological Quality of Quantitative Studies.

Article	Methodological quality assessment of quantitative studies (EPHP)	Global Classification
A3 ⁽²⁰⁾	A - Q1 (Strong) Q2 (Strong); B - Strong (Randomized controlled) C - Q1 (Strong) Q2 (Strong) D - Q1 (Strong) Q2 (Strong); E - Q1 (Strong) Q2 (Strong); F - Q1 (Not applicable) Q2 (Strong); G - Q1 (Strong) Q2 (Strong) Q3 (Strong); H - Q1 e Q 2 (Organization in the community/institution) Q3 (Strong) Q4 (Moderate).	Strong
A4 ⁽⁸⁾	A - Q1 (Strong) Q2 (Strong); B - Weak (Pretest and Posttest); C - Q1 (Strong) Q2 (Moderate); D - Q1 (Strong) Q2 (Strong); E - Q1 (Strong) Q2 (Strong); F - Q1 (Not applicable) Q2 (Strong); G - Q1 (Strong) Q2 (Strong) Q3 (Strong); H - Q1 e Q 2 (Organization in the community) Q3 (Weak) Q4 (Moderate).	Strong
A6 ⁽¹¹⁾	A - Q1 (Strong) Q2 (Strong); B - Weak (Pretest and Posttest); C - Q1 (Strong); D - Q1 (Strong) Q2 (Strong); E - Q1 (Strong) Q2 (Weak); F - Q1 (Not applicable) Q2 (Strong); G - Q1 (Strong) Q2 (Strong) Q3 (Strong); H - Q1 e Q 2 (Organization in the community) Q3 (Weak) Q4 (Strong).	Strong

Source: A Systematic Review of Rural Development Research, Springer Briefs in Public Health⁽¹⁸⁾.

At the end of this selection process, the methodological quality of the studies was evaluated, according to JBI's Feasibility, Appropriateness, Meaningfulness and Effectiveness (FAME)^(15,19). All the articles were evaluated with a high methodological quality. So, they kept being included.

Table 4 - Degree of Recommendation JBI.

Article	Evaluation of methodological quality according to JBI (FAME)				
	F (Feasibility)	A (Adequacy)	M (Meaningfulness)	E (Effectiveness)	Methodological Quality
A1 ⁽²³⁾	Grade A Strong	Grade A Strong	Grade A Strong	Grade A Strong	High
A2 ⁽²²⁾	Grade B Weak	Grade A Strong	Grade A Strong	Grade A Strong	High
A3 ⁽²⁰⁾	Grade A Strong	Grade A Strong	Grade A Strong	Grade A Strong	High
A4 ⁽⁸⁾	Grade A Strong	Grade A Strong	Grade A Strong	Grade A Strong	High
A5 ⁽²¹⁾	Grade A Strong	Grade A Strong	Grade A Strong	Grade A Strong	High
A6 ⁽¹¹⁾	Grade A Strong	Grade A Strong	Grade A Strong	Grade B Weak	High
A7 ⁽¹³⁾	Grade A Strong	Grade B Weak	Grade A Strong	Grade B Strong	High
A8 ⁽²⁴⁾	Grade A Strong	Grade A Strong	Grade A Strong	Grade A Strong	High
A9 ⁽¹²⁾	Grade A Strong	Grade A Strong	Grade A Strong	Grade A Strong	High

Source: New JBI Grades of Recommendation^(16,20).

RESULTS

After the whole process of validating the quality of articles, taking into consideration the objectives of the study and the departure question, nine articles were included in the systematic review.

Tabela 1 – Data Synthesis.

Study identification/ Authors 1 ⁽²³⁾	Aim of the study	Study design	Participants, type and number	Interventions or phenomena of interest	Results	Conclusions
<p>Perceptions of patient education during hospital visit – described by school-age children with a chronic illness and their parents</p> <p>Authors: Marjatta Kelo Elina Eriksson Ilse Eriksson</p>	To explore elements of a significant nursing education event during a hospital visit, described by the parents and the child, at school age, with chronic illness (asthma/allergy, type 1 diabetes mellitus or epilepsy).	Descriptive.	19 Finnish parents (in 4 cases both parents were interviewed together) and their children (12), aged between 5 and 12. (3 children did not participate because of disability associated with illness).	The study reveals the nursing competences that can be applied in the education sessions to schoolchildren with chronic pathology and to their parents.	Schoolchildren with chronic pathology and their parents described significant events in nursing education sessions. They provided interesting visions and challenges for child/family education. The number of positive incidents was higher than the negative ones in the parents' description. Children included both positive and negative features in their stories.	The findings show empirical evidence that nurses responsible for the education of schoolchildren with chronic illness/family should be skilful and demonstrate didactic and interpersonal skills. The study findings provide many practical examples of competency requirements for proper child/family education. These findings may be useful for all nurses who care for children with chronic pathology and their families.

Tabela 1 – Data Synthesis.

Study identification/ Authors 2 ⁽²²⁾	Aim of the study	Study design	Participants, type and number	Interventions or phenomena of interest	Results	Conclusions
<p>Chronic Neurological Conditions In the Classroom: A School Nurse Curriculum For Sustaining a Healthy Learner</p> <p>Authors: Julie Sprague-McRae Ruth Rosenblum</p>	<p>To present a comprehensive and consolidated curriculum in children's neurology for school nurses, developed on the basis of <i>Child Neurology Telephone Encounter Guides</i>.</p>	<p>Narrative/ Opinion of Experts.</p>	<p>-</p>	<p>This curricular program guides school nurses in health care provided to children with neurological disorders through personal or telephone interactions with health care providers, students, and parents.</p>	<p>The curricular program applies the conceptual framework <i>Child Neurology Process-Oriented Triage (ChiNePOT)</i> (Rosenblum & Sprague-McRae, 2009) and <i>The Healthy Learner Model (HLM) for Student Chronic Condition Management</i> (Erickson, Splett, Mullett, & Heiman, 2006) to promote and maintain student's health.</p>	<p>With this curriculum, school nurses acquire more knowledge/skills and are better prepared to care for students with neurological disorders.</p>

Tabela 1 – Data Synthesis.

Study identification/ Authors 3 ⁽²⁰⁾	Aim of the study	Study design	Participants, type and number	Interventions or phenomena of interest	Results	Conclusions
<p>The effect of a modular education program for children with epilepsy and their parents on disease management</p> <p>Authors: Fatma Gürhopur Ayşegül Dalgıç</p>	To evaluate the effectiveness of a modular education program for children with epilepsy and parents in the management of the disease	Experimental.	84 participants in the modular education program (42 children and 42 parents); Control group that did not participate in the program: 50 children and 50 parents. (Including parents and children aged between 7 and 18, with epilepsy for at least 6 months without mental impairment, followed at the pediatric neurology clinic of the university hospital in Antalya, Turkey.	The study provides the structure of the modular program, with 8 modules: 4 for children and 4 for parents.	<p>Children in the intervention group significantly improved their knowledge, self-efficacy on seizures and quality of life, compared to those in the control group.</p> <p>The parents of the intervention group also significantly improved their knowledge about epilepsy, compared to the control group.</p>	<p>The effectiveness of the modular education program for children with epilepsy and their parents on the management of the disease has been confirmed. The results indicate that the use of interactive teaching methods helps children with epilepsy and their parents to improve their knowledge and self-efficiency in case of seizures, thus contributing to the improvement of their quality of life.</p> <p>Nurses working with children with epilepsy and their parents should provide modular education programs on a regular basis.</p>

Tabela 1 – Data Synthesis.

Study identification/ Authors 4 ⁽⁸⁾	Aim of the study	Study design	Participants, type and number	Interventions or phenomena of interest	Results	Conclusions
<p>Increasing Epilepsy Awareness in Schools: A Seizure Smart Schools Project</p> <p>Authors: Heather Brook Cynthia Hiltz Vicki Kopplin Linda Lindeke (Em parceria com a Fundação Epilepsia de Minnesota)</p>	<p>Provide education and resources to school staff to care for schoolchildren with seizures.</p>	<p>Descriptive.</p>	<p>26 nurses (19 with bachelors or masters and 7 with doctorates) from 21 schools in the Midwestern district that have students diagnosed with epilepsy.</p>	<p>School nurses were trained to instruct staff about rendering care to children/youth with seizures.</p>	<p>Most school nurses assessed resources and training interventions as "very helpful". The confidence of the school nurse in caring for students with seizures has increased. The implementation of action plans has increased. In 88% of the children with new diagnoses of seizure, the health documentation in the school was completed.</p>	<p>School nurses played vital roles in raising seizure awareness as educators and caregivers. This project is an example to expand smart school programs of seizures/epilepsy. School nurses should use new resources in the care of children/youth with seizures, a procedural orientation and updating of care plans.</p>

Tabela 1 – Data Synthesis.

Study identification/ Authors 5 ⁽²¹⁾	Aim of the study	Study design	Participants, type and number	Interventions or phenomena of interest	Results	Conclusions
Ethical Issues in School Nursing Authors: Teresa Savage	Review ethical concepts in the context of school health nursing.	Narrative/ Expert Opinion.	-	Ethical theories, ethical principles, ethical decision-making and other relevant concepts, such as moral suffering, moral courage, legislative advocacy and social justice, in school health nursing.	School health nurses should: <ul style="list-style-type: none"> - Use an ethical decision-making model whenever possible; - Use existing resources, even if they are not specifically targeted to school health nursing; - Require education focused on regular ethics specific to school health nursing. 	It is imperative that school health nurses and all professionals in the school environment work together to address the ethical challenges presented. School nurses, individually and collectively, shape the future through diligent care and persistent advocacy of student's rights.

Tabela 1 – Data Synthesis.

Study identification/ Authors 6 ⁽¹¹⁾	Aim of the study	Study design	Participants, type and number	Interventions or phenomena of interest	Results	Conclusions
<p>Effectiveness of Video Assisted Teaching Programme on Epilepsy in Children among the Primary School Teachers in the Selected Schools of Udupi District</p> <p>Authors: Pillai Balakrishna Anjalin D'souza Nidhin Thoma</p>	To evaluate the effectiveness of a video-assisted teaching program in the acquisition of knowledge of primary school teachers in the district of Udupi regarding the care rendered to children with epilepsy.	Experimental.	55 teachers from public primary schools of the Udupi district, selected using the cluster sampling technique. 11 primary schools selected by the simple random technique.	The article also describes results from similar studies with other populations in Indonesia and Bangalore.	There was a significant increase in knowledge assessment results before and after viewing the video. Before, 8 (23.6%) teachers had a "good" knowledge about epilepsy and then 54 (98.20%) were also classified as having a "good" knowledge.	The study revealed that there were deficits of knowledge on the part of teachers on the care for children with epilepsy. The video-assisted teaching program, which can be used by school nurses, has proved to be effective for the acquisition of teachers' knowledge about the causes, prevention and action in case of epileptic crisis. Teachers should be encouraged to learn about child care with epilepsy in order to act correctly and prevent complications.

Tabela 1 – Data Synthesis.

Study identification/ Authors 7 ⁽¹³⁾	Aim of the study	Study design	Participants, type and number	Interventions or phenomena of interest	Results	Conclusions
<p>Challenges of epileptic learners as viewed by educators in rural schools in Limpopo Province, South Africa</p> <p>Authors: N.N. Nefolovhodwe N.J. Ramakuela D.U. Ramathuba</p>	<p>Explore and describe the challenges of having epileptic students, seen by educators in rural schools in Limpopo province, South Africa.</p>	<p>Descriptive.</p>	<p>All teachers working in the 5 primary schools in Limpopo Province who have had (prior to or at the time of the study) students with epilepsy (12 teachers).</p>	<p>Identify the challenges in the care rendered by teachers to the student with epilepsy, in order to find ways to overcome them, and the role of the nurse is crucial in this regard.</p>	<p>2 themes and 6 sub-themes resulted from interviews:</p> <p><u>Topic 1:</u> The stigma and discrimination suffered by students with epilepsy Sub-themes: 1.1 - Stigma and discrimination by teachers; 1.2 - The knowledge deficit of teachers and students; 1.3 - Feelings of embarrassment and embarrassment after epileptic seizures;</p> <p><u>Topic 2:</u> Providing care and support to students with epilepsy Sub-themes: 2.1 - Provision of support by family members; 2.2 - Provision of support by teachers; 2.3 - Overprotection of the epileptic student, by teachers.</p>	<p>This study concluded that students with epilepsy present different problems, in the view of teachers. They present challenges in fighting stigma and discrimination by teachers and peers, as well as overprotection, which prevents them from engaging in activities and consequently socializing with peers. Education to teachers is necessary so that they can have a better understanding about the child with epilepsy.</p>

Tabela 1 – Data Synthesis.

Study identification/ Authors 8 ⁽²⁴⁾	Aim of the study	Study design	Participants, type and number	Interventions or phenomena of interest	Results	Conclusions
<p>A model for internalized stigma in children and adolescents with epilepsy</p> <p>Authors: Joan Austin Susan Perkins David Dunn</p>	To test relationships in a model that identified variables strongly associated with the perception of stigma in children and adolescents with epilepsy.	Observational.	173 children and adolescents with epilepsy participated (85 girls and 88 boys, aged between 9 and 14).	The need for information and support related to epilepsy was measured using the <i>Child Report of Psychosocial Care</i> scale. The type of information needing measurement in this scale includes the causes of seizures, medication, and physical activity limitations. The type of support measured on this scale is mainly emotional support (need to talk about feelings, about having epilepsy, discussing your worries and fears, and get help dealing with seizures in school).	<p>The mean <i>stigma</i> score was 2.24 on the scale of 1 to 5;</p> <p>The mean score of the measure of <i>fear and concern</i> was 2.61 on the scale of 1 to 5;</p> <p>The mean score of <i>self-efficacy for management and control of the seizure</i> was 4.15 on the scale of 1 to 5;</p> <p>The mean score for the <i>need for information and support</i> was 1.83 on a scale of 1 to 3.</p>	Stigma perceptions are associated with two potentially psychosocial interventions: fear and concern about having epilepsy and the need for information and support. Future research should test the effectiveness of interventions that reduce fear and despair, information about epilepsy and help children learn more about their needs.

Tabela 1 – Data Synthesis.

Study identification/ Authors ⁹⁽¹²⁾	Aim of the study	Study design	Participants, type and number	Interventions or phenomena of interest	Results	Conclusions
<p>The stigma experiences and perceptions of families living with epilepsy: Implications for epilepsy-related communication within and external to the family unit</p> <p>Authors: Ailbhe Benson Stephanie O'Toolea, Veronica Lambert Pamela Gallagher Amre Shahwan, Joan Austin</p>	<p><u>General objective:</u> To present the experiences of stigma of the child with epilepsy and of their parents in the context of communication about epilepsy inside and outside the family unit.</p> <p><u>Specific objectives:</u> - Explore the experiences of children with epilepsy and their parents regarding stigma; - Examine the perception of stigma, the relationship between children and parents, demographic variables, types of seizure, and epilepsy-related communication inside and outside the family unit.</p>	Descriptive.	<p><u>Phase 1:</u> 33 Children with epilepsy and 40 parents</p> <p><u>Phase 2:</u> 47 Children with epilepsy and 72 parents.</p>	<p>The health professional (nurse) plays a vital role in establishing communication strategies about epilepsy with families. Children and their parents should be taught how to initiate, manage and maintain open conversations about epilepsy in order to contribute to their psychosocial well-being.</p>	<p><u>Phase 1:</u> Obtained 6 themes, according to the experiences of stigma reported by children and parents: - Social exclusion; - Restriction of activities; - Making fun/Bullying attitude; - Internalisation of negative feelings regarding epilepsy; - Concealment; - Stigma-Coaching.</p> <p><u>Phase 2:</u> The greater perception of stigma in children was associated with greater perception of stigma by their parents. Stigma perceptions of children were significantly correlated with their gender, frequency of seizures, time since diagnosis, type of crisis, and family communication.</p>	<p>This study reveals that stigma remains a major challenge in the lives of children/young people with epilepsy and their families. Family communication about epilepsy, within and outside the family context, has significant implications in this regard. While many children with epilepsy and their parents deal with the stigma surrounding the condition, some may inadvertently contribute to the silence which surrounds epilepsy by concealing diagnoses and/or engaging in limited family dialogues about epilepsy.</p>

SYNTHESIS OF RESULTS

Care given to a child/youth care with epilepsy requires the approach of a multidisciplinary team. In this team, the specialist nurse in children's health and paediatrics, who is closer to the child/youth and the family, has training and skills that give him/her important responsibilities⁽²⁰⁾.

The school health nurse, who specializes in child health and paediatrics, is in a privileged position to play this role, since he/she has a wide variety of knowledge to evaluate, care for or refer the sick child/young person, as well as the capacity to act in emergency situations that may occur in a school context. Beyond this wide variety of knowledge, this nurse must also know the rules, policies and regulations that apply to the educational environment. Its overall goals include promoting health, safety and students' learning^(8,21).

The special health needs of students with neurological disorders require the school health nurse to maintain a high level of specialization. As a consequence, he/she should keep his/her ongoing training process active and enrich his/her curriculum in what this area of knowledge is concerned^(8,22).

Sprague-McRae and Rosenblum (2013), present us with a comprehensive and consolidated curriculum in childhood neurology specifically for school health nurses, developed according to the *Child Neurology Telephone Encounter Guides*⁽²²⁾.

This program guides school health nurses in health care to children/youth with neurological disorders. It combines a complete basis of knowledge, skills of data collection and clinical judgment, to adequately interpret data and make care safe and effective⁽²²⁾.

The program provides tools for nurses to enable students with chronic conditions to maintain attitudes that promote their health at school so as not to disrupt the learning context. Aspects of general and psychosocial health, family dynamics, coping, identification of symptoms, therapeutics care, treatments, early intervention, behaviours in school context, therapy programs, articulation with other health professionals accompanying the child/youth and updating their individual health plan⁽²²⁾ are described.

The school health nurse lives in two interrelated worlds: that of education and that of nursing⁽²¹⁾. Literature indicates that the education of a child/youth requires educational creativity⁽²³⁾. The current clinical guidelines for the care rendered to a child/youth with epilepsy emphasize nursing models that should include child/youth-centred training^(20,23).

The child health specialist nurse finds, in his/her daily reality, the need to care for the child/young person and for the family as a whole. When these nurses provides school health care, they should direct their practice to help the child/youth and their parents to effectively control the disease⁽²⁰⁾, but they also play an active role in teaching teachers/school staff, since they are the ones who remain with the child/youth throughout the whole school hours⁽¹¹⁾.

It is important that teachers/staff are properly informed about the illness and encouraged to have a positive attitude towards the child/youth, in order to soothe fears and to demystify misconceptions, promoting the maintenance of their quality of life. They should also transmit this attitude to the rest of the students, so that everyone disseminates this information to family, friends and to the community^(11,13).

In 2015, Nefolovhodwe, Ramakuella, and Ramathuba conducted a study to identify the challenges encountered by teachers in the care given to students with epilepsy, so as to find a way to overcome them. The identified challenges were related to stigma, discrimination experienced by students (“stigma and discrimination on the part of teachers”, “teacher and student knowledge deficit” and “feelings of shame and embarrassment after epileptic seizures”) and with the provision of care and support to students with epilepsy (“provision of support by family members”, “by teachers” and “overprotection of the epileptic student by the teachers”)⁽¹³⁾.

These challenges felt by teachers require periodic training and education on epilepsy, promoting health within schools. Thus, the intervention of the school health nurse, specialist in children's health and paediatrics is directed to a triad: child/youth, parents and school community.

The strategies used by the nurse to achieve these goals can be numerous, such as the provision of education and training programs, provision of support material and organization of group meetings with children/youth and parents with epilepsy^(8,12,20).

In addition to using these tools, the school health nurse must have educator skills. He/she should demonstrate interpersonal skills and abilities, using a variety of teaching methodologies, be creative and encourage all students, fundamental characteristics of a good educator⁽¹²⁾.

In a study conducted in Finland (Helsinki), to find out the characteristics of nurses who are good educators in the perception of children/young people with chronic illness in school age and parents, the findings showed empirical evidence that the nurses responsible for the education of child/youth and family should be skilled and have didactic and interpersonal skills⁽¹²⁾.

The skills of a good educator nurse involve the ability to create an environment that promotes learning; communicating with the students, being the communication adjusted to their level; encouraging the participation of the child/youth and the parents; establishing and maintaining a dialogue; demonstrating empathy, calm, encouraging and non-intimidating behaviour and respecting the family and their privacy by giving them the time they need.

The good educator nurse should define the context for learning, have in-depth knowledge of the disease, diagnose learning problems, promote personal responsibility for the self-management of the disease, supplemented with parental support and promote learning with appropriate methods⁽¹²⁾.

Modular education programs for children/young people with epilepsy and their parents have been used in Germany, Switzerland and, recently, in Turkey. The teaching materials and methods used were: slides, support guides for children/youth and parents, videos (on living with epilepsy: occurrence of epileptic crisis and crisis management at home, on vacation and at school), role playing, demonstration, debates, discussion, questions and answers, drawings and narration^(20,24).

These modular education programs used with interactive teaching methods were effective because they increased the knowledge of parents and children/young people and, consequently, their self-efficacy and quality of life⁽²⁰⁾.

A study conducted in 2016 at primary schools in the Udipi district confirmed the effectiveness of using a video program, about 10 minutes long, as an education instrument on epilepsy for teachers. In the video, the causes of epilepsy, clinical characteristics, treatment, effects of therapy, how to act in the event of a seizure, and the role of the teacher in the care rendered to the child/youth with epilepsy were transmitted⁽¹¹⁾.

In the Czech Republic, education on epilepsy using an animated video or educational drama has shown to improve knowledge about the pathology and to reduce the associated stigma in children/youth⁽²⁴⁾.

In the USA, in 2016, Brook, Hiltz, Kopplin and Lindeke, in a partnership with the Minnesota Epilepsy Foundation, developed a new program, based on the work by Austin et al. (2010), aimed at educating school communities about convulsions, in order to create safe, supportive environments for students with epilepsy⁽⁸⁾.

The goal was to keep students healthy, when surrounded by a team with tools and knowledge about epilepsy. In this project several measures were taken to adapt the response to epileptic seizures/convulsions in a school environment. The nurses were educated and later taught the school staff to recognize and act in case of a convulsion; a school district website was created on the subject, where employees, parents and students accessed information on epilepsy; some interventions were carried out with families; some staff have implemented action guidelines/crisis management plans, and student health plans have been developed and updated, including emergency plans in case of seizures⁽⁸⁾.

According to the study's reports, the health plan of the student with epilepsy should be built in collaboration with the nurse, parents and teachers. It should include specific information on the characteristics of the seizures, precipitating factors, frequency, duration, when the emergency services should be contacted, among other aspects. It should contain a plan of action describing the child/youth care in case of a convulsion and it should be updated annually or more frequently if necessary⁽⁸⁾. The child/youth health plan can be considered an instrument, where all caregivers use a universal language.

Besides all the intervention of those around the child/youth, he/she must be himself/herself involved in his/her illness process. The nurse should not only inform the child/young person, but also provide him/her with the opportunity to express himself/herself. In this way, he/she enables him/her to talk about his/her pathology and knows his/her perception of it. The nurse can promote the use of verbal and non-verbal methods (e.g. drawings) for the child/youth to express himself/herself⁽²⁰⁾.

Parents often conceal the illness, even from close relatives. These may inadvertently contribute to the silence surrounding epilepsy through concealment of diagnosis, stigma-coaching, and/or engaging in a limited family dialogue about epilepsy. Thus, children/young people cannot access the exact knowledge and they adopt incorrect practices^(12,20,24).

Benson et al., in 2016, presented a study on stigma experiences and on the perceptions of families of children/youths with epilepsy, where the implications of communication related to epilepsy within and outside the family unit were addressed⁽¹²⁾.

Six subjects were obtained, according to stigma experiences reported by children and their parents: social exclusion, restriction of activities, joy/bullying attitude, internalization of negative feelings towards epilepsy, concealment and stigma-coaching. The greater perception of stigma in children was associated to a greater perception of stigma by their parents⁽¹²⁾.

Austin, Perkins and Dunn, in 2015, developed a model that identified variables strongly associated with perceived stigma in children/youth with epilepsy, potentially amenable to psychosocial interventions. The results suggested that the perception of stigma is mainly associated with two variables: “fear and concern about having epilepsy” and the “need for information and support”⁽²⁴⁾.

In both studies, the following factors were significantly correlated with greater perceptions of stigma: age (younger), gender (female), frequency and severity of seizures, short time elapsed since diagnosis, having at least one seizure in the previous year, low self-efficiency for crisis management and reduced family communication^(12,24).

The perception of stigma associated with less communication about the disease within the family and greater concealment outside the family environment shows that stigma remains a major challenge in the lives of families living with childhood/juvenile epilepsy⁽¹²⁾.

These findings provide a basis for the development of interventions that may help the child/youth to cope with their health condition⁽²⁴⁾. The school health nurse should promote interventions that reduce fear and concern, such as providing information and emotional support, as well as creating social spaces for the child/youth with epilepsy and their parents to establish a dialogue, to communicate with other children/youth with epilepsy and to discuss fears/concerns^(12,24).

In the pursuit of the student's health promotion, the school health nurse may also encounter innumerable ethical problems and he will rarely find literature that includes direct answers to these questions, since in Portugal there is no specific code of ethics for school health nurses, such as that of the *National Association of School Nurses* (NASN) (2016), in the USA⁽²¹⁾.

In his review of literature, Savage (2017) addressed this gap by exploring different ethical concepts in the context of school health nursing: ethical decision-making, ethical principles and relevant concepts such as moral suffering, moral courage, legislative advocacy, social justice, consent and confidentiality, where recommendations/resources for the school health nurse were included. He referred to two ethical theories (utilitarianism and deontology) and four common principles (autonomy, beneficence, non-maleficence and justice) presented in the context of school health nursing⁽²¹⁾.

Apart from the mentioned contents, Savage offers several recommendations for school health nurses facing ethical dilemmas in practice: he suggests the use of an ethical decision-making model whenever possible, even if it is not specific to the school context. He encourages the capacity to adapt and to take advantage of the existing resources, requiring regular training in specific ethics for school health nursing⁽²¹⁾.

FINAL CONSIDERATIONS

Health is essential for the student's learning process, and the school health nurse is a vital resource to promote and maintain the student's health. This professional accompanies the child/youth throughout his/her learning process and is therefore in the ideal context to provide ongoing support.

The school health nurse must deepen knowledge and develop skills, contributing for the improvement of quality of care for all students, healthy or with special health needs.

The specialization in children's health and paediatrics attributes specific competencies such as the capacity to implement and manage health plans; recognition and delivery of nursing care in situations of instability of vital functions and risk; responsiveness to rare diseases and promotion of child/youth and family adaptation to chronic illness, disability/incapacity⁽²⁵⁾.

Although this nurse possesses high skills, maintaining his continuous training process is essential to consolidate knowledge, according to the specific needs that he/she finds in his/her practice, such as those of the child/youth with neurological disorder: epilepsy.

The school health nurse also has enormous ethical challenges to address, according to the breadth of paediatric conditions, as well as of the rules, regulations, policies and laws governing nursing and the educational environment. Individually and collectively, he/she should help build the future by fostering diligent care and persistent struggle for students' rights.

In order to promote the quality of care for the child/youth with epilepsy, the nurse directs his/her intervention to the triad child/youth, parents and school community.

Education is necessary to promote adequate care, support and timely management, preventing complications. Therefore, the nurse must demonstrate didactic and interpersonal skills. He/she has the role of identifying the individual needs of the child/youth and parents, and of building a personalized education process. He/she should define the intervention priorities, selecting the appropriate methodology for each family, individually.

The literature shows that the modular education programs using interactive teaching methods are important tools for children/youth, parents and teachers. Video programs, debates, role playing, demonstration, discussion, questions and answers, drawings and narration can also be methodologies used to educate and demystify.

Parents and teachers occupy an important position in the concept of stigma, perceived by children/young people with epilepsy. A limited communication about the pathology, both inside and outside the family unit, is effectively associated with feelings of stigma. Providing information on epilepsy, helping the child/youth to know their need for support, promoting interventions to help families interact and discuss epilepsy, both within and outside the family unit, contributes to improve the psychosocial well-being of the child/youth and of their parents.

The nurse must develop his/her actions to break this cycle of invisibility and dispel myths by raising public awareness and understanding of epilepsy. With this purpose, he/she can create social spaces to promote the dialogue of the child/youth and their parents, essential for this achievement.

According to the above, it is imperative to build an individual health plan for the child/youth with epilepsy, where everyone communicates in a common language. This plan results from a partnership between the school health nurse, parents and teachers and it distinguishes all planned care, including the education, communication and articulation processes with hospital and community care. Health promotion will only be effective if we achieve this magnitude, intervening at a biological and psychosocial level, in order to provide a school environment which is healthy and fruitful to the learning process.

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