

Children and Youth with Life-Limiting or Life-Threatening Conditions – Overview of the Topics of Educational Practice: A Scoping Review

Martina Haroková¹, Jan Chrastina¹

¹Institute of Special Education Studies, Faculty of Education,
Palacký University Olomouc, Olomouc, Czech Republic

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CORRESPONDING AUTHOR:

Martina Haroková;
martina.harokova01@upol.cz

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ABSTRACT

Objectives: The scoping review (ScoRev) presents the literature relating to the education of children and youth with life-limiting conditions (LLC) and life-threatening conditions (LTC) and identifies and describes the topics that appear in the literature. **Method:** The scoping review was conducted based on Arksey and O'Malley's 5-stage framework. In a total of five databases, ProQuest, ERIC, Web of Science, Scopus, and EBSCO Discovery Service a combination of keywords was used to identify 14 records published in 2002-2018 that corresponded to the ScoRev selection criteria. These records were then analyzed in terms of content and classified into thematic categories and subcategories. **Results:** The ScoRev selection consisted of a dissertation and thirteen journal articles. A well-elaborated topic of the studies related to the teacher's roles, experiences, and needs in the education of a child with LLC or LTC. Other topics included the challenges in the education of these children, intervention, or death of a child in school. The topic of education of students with life-limiting or life-threatening conditions is most frequently assessed from the teacher's perspective. **Conclusion:** The results of the ScoRev may suggest a lack of available resources that would reflect the current practice of educating children and youth with LLC and/or LTC on a general basis.

Keywords: life-limiting and life-threatening conditions, children and youth, scoping review, education, intervention, school

INTRODUCTION

Over the past twenty years, the number of children and youth with life-limiting and life-threatening conditions (referred to as LLC and LTC) educated in mainstream elementary and secondary schools has increased (Ekins et al., 2017). This is mainly due to the continuous development of medicine, technological progress, and ongoing inclusion (Robinson & Summers, 2012). Therefore, educating these children requires thorough preparation and planning which requires a multidisciplinary team's involvement (Heller et al., 2013). Its members are usually the teacher (teachers), the school director, the student with LLC or LTC, the student's family, the psychologist, and other medical and non-medical professionals (Shaw et al., 2010; Vanclooster et al., 2018). During the entire educational process, it is necessary to respect the complex needs of children with LLC and LTC related to their physical, mental, social, and emotional health (Robinson et al., 2018). These needs may differ between students depending on the specifics of their diagnoses, socio-cultural context, psychosocial support as well as their family background.

There are a variety of life-limiting and life-threatening conditions that teachers may encounter as part of their practice. Chambers (2018) classifies these conditions into the following four categories: (1) life-threatening conditions for which curative treatment may be feasible but can fail (cancer, organ failure of the heart, liver, etc.), (2) conditions in which premature death is inevitable (cystic fibrosis, Duchenne muscular dystrophy, type 1 spinal muscular atrophy), (3) progressive conditions without curative treatment options (Batten disease, mucopolysaccharidoses), (4) irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and the likelihood of premature death (severe complex cerebral palsy disabilities following for example brain or spinal cord injury). Regarding the fact that these are serious diagnoses, it is advisable to have a school nurse in the school team to support not only children with LLC or LTC but also other students and teaching staff (Brunt, 2018; Ekins et al., 2017).

Foreign studies show that the successful inclusion of children with LLC and LTC in school may have a positive impact on the quality of their life, well-being, and psychosocial growth (Bessell, 2001; Kliebenstein & Broome, 2002; Nabors, 2014; Webb, 2009). Students with a serious disease who go to school and participate in daily routine activities with their peers gain a sense of normality (Bessell, 2001; Kaffenberger, 2006). Many of these children may suffer from self-concept issues as a result of

their disease (Vágnerová, 2014). Thanks to appropriate interventions, the child may experience success in school and a positive experience that may contribute to strengthening the child's self-confidence (Hayman et al., 2002). Therefore, Webb (2009) recommends that schools should develop methods and strategies that encourage respect and support for the child with LLC or LTC and build resiliency and a positive climate for adaptation.

Education of children with LLC and LTC entails certain specifics and challenges. As a result of their health condition, a few children need to be hospitalized (Adistie et al., 2020). This is closely related to the children's absence in school, which typically has a negative effect on their psyche but also academic results (Asprey & Nash, 2006). Children in long-term hospitalization are deprived of peer socialization and educational structure which is part of everyday life (Kaffenberger, 2006). Some children may have difficulty fitting among their classmates and establishing stable peer relationships and may feel isolated (Brunt, 2018; Nabors, 2014). Another specific feature relates to medical crises within the class setting. The most critical moment in the education of some children with LLC or LTC is the death of the child during the school year. Teachers are expected to respond to these situations in an appropriate way, understand the special educational needs of the child with LLC or LTC as well as other specifics arising from his/her current health condition, be able to work with the child's classmates and support other students, the family of the deceased student and colleagues (Heller et al., 2013).

AIM AND METHODS

The aim of the paper was to identify, describe and analyse the currently available literature relating to the education of children and youth with life-limiting or life-threatening conditions in accordance with the defined criteria and to make an overview of the topics from various perspectives.

The following research questions were formulated for the ScoRev:

- (1) Which topics are included, analysed and described in the relevant available literature?
- (2) Which perspective is most frequent in the relevant literature?

Design

The scoping review (ScoRev) was developed based on Arksey and O'Malley's methodology (2005). The process consisted of the following five stages: (1) identification of

the research questions, (2) identification of the relevant literature, (3) selection of the literature for classification and data extraction, (4) mapping and sorting of the data, (5) comparison, summarization, and presentation of the results. The procedure for the processing and analysis of the literature included in the scoping review is presented in the form of a PRISMA flow diagram (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) (Page et al., 2021).

Methodology

ScoRev is used to map the available literature concerning a particular topic considering the nature and quantity of the literature (Arksey & O'Malley, 2005). Another purpose of a ScoRev is to summarize and synthesize/analyze the available knowledge or to identify specific literature to define practical recommendations (Chrastina, 2019). The search strategy of this ScoRev was based on the pre-defined inclusion and exclusion criteria, selected keywords, and their combinations. The identified full texts were downloaded and browsed to determine their relevance with respect to the aims and questions of ScoRev. The records were analyzed and synthesized using the elements of content and thematic analysis.

Eligibility criteria

For the purposes of the ScoRev, records in English were searched according to the following criteria: (1) literature in English, (2) full texts, (3) child or youth younger than 25 years with LLC or LTC, (4) text relating to the process of education, (5) presence of the terms “life-limiting condition(s)” and/or “life-threatening condition(s)” or their synonyms “life-limiting illness/disease” and/or “life-threatening illness/disease”, (6) text published in 2002–2022. Any records meeting the following criteria were excluded: (1) texts in a different language than English, (2) non-full-text literature, (3) literature focused on persons with LLC and/or LTC older than 25 years, (4) studies/literature focused on the education of parents, health professionals or social workers, (5) children and youth with chronic issues (chronic conditions, chronic disease, chronic illness) or with health needs (special health needs), (5) texts focusing only on a single specific diagnosis of life-limiting or life-threatening conditions (mostly case studies), (6) interventions not directly related to the education process, (7) study/literature published before 2002, (8) scientific paper based on critical assessment (judgement, review, polemic, etc.), (9) unavailable study/literature. The criteria were applied in the following chronology: study/literature search – verification of the

source (a record) – assessment of relevance based on titles and subsequently abstracts – the presence of LLC/LTC terminology in relation to childhood/youth and education – parallel review by the co-author of this ScoRev.

In the context of this ScoRev, literature focused on the education of children/youth with LLC/LTC is understood as any professional text (study, book, thesis, etc.) that provides information on the education of children or youth with LLC and/or LTC as follows: (1) focus on children or youth with LLC or LTC (special educational needs, evaluation, development, intervention), (2) focus on teachers and other school staff (experience, readiness, preparation, needs, education, opinions, attitudes), (3) focus on the educational environment (primary school, secondary school, mainstream school, college, high school, hospital school, special school, aspects supporting a stimulating environment).

Search strategy

A total of five databases accessible to Palacký University Olomouc, Czech Republic were used to search for relevant records. They were the following databases: (1) EBSCO Discovery Service (EDS) multi-search engine, (2) ProQuest, (3) ERIC, (4) Web of Science, and (5) Scopus. Repeated searches for the records were performed in parallel by both authors of this ScoRev during the period 07/2021–11/2021. The search procedure focused on the relevant full texts in English without a time limitation. Different combinations of the following keywords using the AND/OR operators were used: (“life-limiting conditions” OR “life-limiting conditions” OR life-limiting illness OR life-limiting OR “life-threatening conditions” OR “life-threatening conditions” OR life-threatening illness OR life-threatening OR life-shortening conditions OR life shortening OR terminal illness) AND (child* OR kid* OR pupil* OR student* OR adolescent*) AND (school* OR education OR educat* OR classroom OR class* learn* OR practice OR policy OR teach* OR support* OR intervention OR evaluation OR integration OR inclusion). A precondition was the presence of the keywords in the title or abstract. The initial summary search was performed using the EBSCO Discovery Service (EDS) multi-search engine. In the second stage of the search, additional records were identified in the existing database. Subsequently, a targeted search for the full texts was performed in the ProQuest, Eric, WOS, and Scopus databases. During the third stage of the search, the reference lists of the identified literature were analyzed, and the studies were included in the ScoRev selection. The entire search process is shown in Fig. 1.

Study selection including PRISMA flow diagram

In the selected electronic databases, a total of 2,543 records that met the selection criteria were identified. After deduplication, the number of records was reduced to 1,778. These records were screened for titles and abstracts by both authors of the ScoRev. During this stage, a total of 1,704 irrelevant records were excluded. The remaining 74 records were examined based on the inclusion and exclusion criteria. 9 records were excluded. In the next stage, both authors of the ScoRev read the full texts of the remaining records and studied their reference lists (additional 22 relevant resources were found). Of the total number of 87 records, 73 were excluded because they did not address the education of children/youth with LLC and/or LTC on a general basis or did not contain the LLC/LTC terminology (on a general basis). After these records were excluded, a total of 14 full texts remained that met the criteria as defined above and were included in the final sample of the ScoRev selection. They included a dissertation and 13 journal articles. The process of literature selection was carried out according to the PRISMA methodology and is shown in Fig. 1.

Data extraction and evaluation of article quality

The records in the ScoRev sample selection were first thoroughly assessed according to the inclusion and ex-

clusion criteria. Data extraction was performed by means of a systematic approach. Subsequently, significant data related to the ScoRev questions were retrieved by content analysis and thematic analysis methods. The data were collected, analyzed, classified, and thematically categorized into clear tables developed by the authors of the ScoRev (see below). In the first stage, the formal attributes (descriptive categories) of full texts were quantitatively evaluated using an identification approach, see Tables 1 and 2. The attributes were as follows: (1) title of the text, (2) author(s), (3) year of publication, (4) country in which the study was conducted, (5) type of literature, (6) resource, (7) type of scientific procedure, (8) type of research, (9) methods, (10) research sample (including quantity), (11) LLC/LTC terminology used, and (12) context. In the second phase, a qualitative content analysis of the full texts combined with some of the elements of the thematic analysis approach was performed to identify the topics (described and examined). The parts of the text were inductively coded using the keywords/codes and the data obtained were subsequently classified by the authors into thematic categories and subcategories. A conceptual approach was used to identify the LLC/LTC terminology used. The results concerning the topic concepts and their frequencies are shown in Tables 3 and 4. The data were collected using Microsoft Excel.

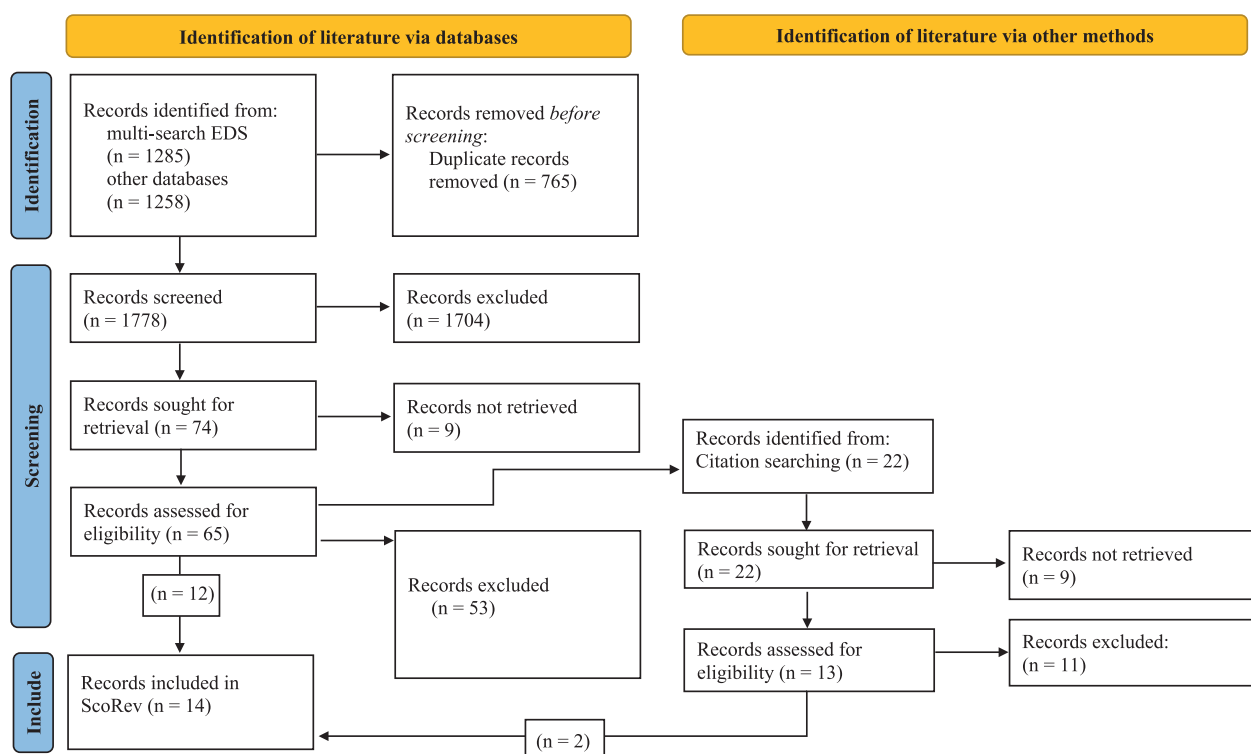


Fig. 1. The process of searching for and selecting studies for the scoping review

RESULTS

The ScoRev selection of literature records on the education of children and youth with LLC and/or LTC consisted of a dissertation and thirteen journal articles (all the attributes of the ScoRev literature selection are presented in Tables 1 and 2.). This topic was most frequently examined from the perspective of teachers in mainstream and special schools (n=8). Only one study focused on the experience of school nurses; some studies analyzed parents' views of the education of their children with LLC or LTC (n=3).

Key topics in studies

Regarding the most frequent research sample, the topics of the studies mostly included the experience, needs, readiness, attitudes, and opinions of teachers regarding the education of children with LLC and LTC (Table 4). Other topics included for example the absence and hospitalization of a child with LLC and/or LTC, the impact of LLC or LTC on the child's education and needs or topics closely related to the child's classmates. A frequent topic in the studies related to the challenges associated with the education of children with LLC and/or LTC, intervention strategies, multidisciplinary collaboration, and the issue of a child's death in school. The studies which focused on the issue of the death of a child with LLC or LTC included specific recommendations for practice. On the contrary, the importance of education for children with LLC and LTC, and their behaviour in school or teacher's assessment were rare. The opinions of children and youth with LLC/LTC concerning the process of education were not present at all. A summary of the key topics concerning the education of children and youth with LLC and LTC in the studies is shown in Table 3 and Table 4.

DISCUSSION

The aim of the scoping review was to identify, describe and analyze the currently available literature relating to the education of children and youth with life-limiting or life-threatening conditions (on a general basis). The main objective was to make an overview of the topics from the available perspectives which appear and are analyzed in the relevant literature. The ScoRev literature selection did not include papers focusing on the education of children with a specific LLC or LTC diagnosis (for example case studies) or on the education of children and youth with a chronic disease. In the selected electronic

databases, a total of 14 records that met the ScoRev literature selection criteria were identified. They included a dissertation and thirteen journal articles published from 2002 until 2018.

In the available literature, the education of children with LLC and/or LTC is mostly examined from the perspective of teachers in mainstream and special schools (n=8). These research studies reflect on their readiness, competencies, attitudes, experiences, and opinions regarding the education of students with LLC or LTC. It has been confirmed that the teacher plays a crucial role in the process of education of a child with LLC or LTC. It is the teacher who uses various strategies to create a stimulating environment for the child's academic and psychosocial development (Lum et al., 2017). According to some studies, more than half of teachers have not felt sufficiently prepared to face the challenges associated with educating students with LLC or LTC over the past twenty years and would appreciate adequate support (Brunt, 2018).

The challenges that teachers often face include, for example, sudden life-threatening conditions in the classroom or communication with other children in the class about the LLC or LTC diagnosis (Papadatou et al., 2002a). What often happens is that other children are not adequately informed about the health condition of their classmate with a serious disease. This may cause interpersonal problems or misunderstandings in the class (Vanclouster et al., 2018). Some teachers may have to face curious questions from their students or directly the child with LLC or LTC regarding his/her diagnosis as well as life and death issues (Heller et al., 2013). The studies suggest that only a small percentage of teachers feel competent to discuss these difficult issues with children. A study by Papadatou et al. (2002a) revealed that only 17% of 340 teachers had a class discussion about the diagnosis and therapy of a child with LLC or LTC.

The most controversial but still well-described issue in the ScoRev literature is the death of a child with LLC or LTC in school. In this situation, it is necessary to adopt adequate strategies for working with the class so that other children handle the death of their classmate in a healthy and adequate way (Franclová & Plachá, 2019). At this point, the school could function as a safe environment open to questions, discussions, and the process of mourning (Goldman, 2015; Heller et al., 2014). Practice shows that supporting a grieving child exceeds the usual requirements for the role of the teacher (Brunt, 2018). Moreover, undergraduate teacher training does not pre-

Table 1. SCharacteristics of the ScoRev literature selection.

	Title	Author(s)	Year of publication	Country*	Type of literature	Source
1.	Children with a Chronic and Life-Limiting Condition: Teachers' Perceptions and Experiences Regarding Students' School Integration	Papadatou, Metallinou, Hatzichristou, Pavlidi	2002a	Greece	Journal article	Illness, Crisis & Loss
2.	Suffer the Children: An Examination of Psychosocial Issues in Children and Adolescents With Terminal Illness	Stillion, Papadatou	2002	USA	Journal article	American Behavioral Scientist
3.	Supporting the bereaved child: teacher's perceptions and experiences in Greece	Papadatou, Metallinou, Hatzichristou, Pavlidi	2002b	Greece	Journal article	Mortality
4.	Preparing Classroom Teachers for the Impending Death of a Student with Terminal Illness	Rice, Gourley	2003	USA	Journal article	Physical Disabilities: Education and Related Services
5.	Access to education for children and young people with medical needs: a practitioner's view	Seymour	2004	UK	Journal article	Child: Care, Health & Development
6.	School Reintegration for Children in Different Phases of Serious Illness	Botcheva, Hill, Kane, Grites, Huffman	2004	USA	Journal article	The Journal of School Health
7.	Teachers Grieve! What Can We Do for Our Colleagues and Ourselves I When a Student Dies?	Munson, Hunt	2005	USA	Journal article	TEACHING Exceptional Children
8.	The importance of awareness and communication for the inclusion of young people with life-limiting and life-threatening conditions in mainstream schools and colleges.	Asprey, Nash	2006	UK	Journal article	British Journal of Special Education
9.	Schooling of children with a life-limiting or life-threatening illness	Craig, Boden, Samuel	2012	UK	Journal article	European Journal of Palliative Care
10.	An evaluation of the educational support for teachers who teach children with life-limiting illness in schools	Robinson, Summers	2012	UK	Journal article	Pastoral Care in Education
11.	Teacher's knowledge and support systems regarding students with terminal illness	Heller, Coleman, Best, Emerson	2013	USA	Journal article	Physical Disabilities
12.	Supporting Children With Life-Threatening Conditions in the Schools	Heller, Coleman, Best, Emerson, Garrett	2014	USA	Journal article	Journal of Hospice & Palliative Nursing
13.	Teachers' experience of working with children with life-limiting conditions in special schools	Brunt	2018	UK	Doctoral thesis	Durham e-theses
14.	Teachers communicating about life-limiting conditions, death and bereavement.	Robinson, Ekins, Durrant, Summers	2018	UK	Journal article	Pastoral Care in Education

* Country in which the research was carried out

Table 2. Characteristics of the ScoRev literature selection

Author(s)	Year of publication	Type of scientific procedure	Type of research	Methods	Research sample	LLC/LTC terminology	Context
Papadatou, Metallinou, Hatzichristou, Pavlidi	2002a	empirical	quantitative	questionnaires	Greek teachers (1792)	life-limiting conditions/disease	elementary schools, junior high schools, high schools
Stillion, Papadatou	2002	theoretical	-	-	-	life-limiting conditions, life-threatening conditions/illness	-
Papadatou, Metallinou, Hatzichristou, Pavlidi	2002b	empirical	quantitative	questionnaires	Greek teachers (1792)	life-limiting health conditions	-
Rice, Gourley	2003	theoretical	-	-	-	life-threatening conditions	schools
Seymour	2004	theoretical	-	-	-	life-threatening conditions	-
Botcheva, Hill, Kane, Grites, Huffman	2004	empirical	qualitative	semi-structured interviews, telephone interview	service providers, parents	life-threatening illness, life-threatening medical conditions	-
Munson, Hunt	2005	theoretical	-	-	-	life-limiting conditions	schools
Asprey, Nash	2006	empirical	-	semi-structured interviews	parents (46)	life-limiting conditions, life-threatening conditions	primary schools, secondary schools, colleges
Craig, Boden, Samuel	2012	theoretical	-	-	-	life-limiting illness, life-threatening illness	schools
Robinson, Summers	2012	theoretical	-	-	-	life-limiting illness	mainstream schools
Heller, Coleman, Best, Emerson	2013	empirical	quantitative	questionnaires	special education teachers (190)	life-limiting conditions	-
Heller, Coleman, Best, Emerson, Garrett	2014	empirical	quantitative	questionnaires	school nurses (303)	life-threatening conditions	schools
Brunt	2018	empirical	qualitative	semi-structured interviews	teachers (18)	life-limiting conditions	special schools
Robinson, Ekins, Durrant, Summers	2018	empirical	quantitative/qualitative	individual (38) and group interview, questionnaires (90)	teachers	life-threatening illness, life-limiting conditions	mainstream schools

Table 3. Topics in the ScoRev literature

Author(s)	Year of publication	Access to education	Inclusion	Policy	Assessment of a child with LLC/LTC in school	Importance of education	Challenges in the education of children with LLC/ LTC	Absence/hospitalization	Interventions/strategies	Impact of LLC/LTC on child education	Needs of a child with LLC/LTC	Psychological specifics of a child with LLC/LTC	Behaviour of a child with LLC/LTC in school	Classmates/relationship with a child with LLC/LTC	School health provision	Parents' experience/ perspective/concerns	Topic of death/death of a child with LLC/LTC in school	Death education	Multidisciplinary cooperation
Papadatou, Metallinou, Hatzichristou, Pavlidi	2002a	X	X		X	X	X	X	X	X			X	X					
Stillion, Papadatou	2002	X				X	X	X	X		X	X			X		X		
Papadatou, Metallinou, Hatzichristou, Pavlidi	2002b						X		X					X			X	X	
Rice, Gourley	2003	X	X				X		X								X	X	X
Seymour	2004	X	X	X			X	X	X										X
Botcheva, Hill, Kane, Grites, Huffman	2004	X		X			X		X	X						X			X
Munson, Hunt	2005						X		X								X	X	
Asprey, Nash	2006	X	X				X	X	X	X		X		X	X	X			X
Craig, Boden, Samuel	2012		X			X	X	X	X	X	X	X			X		X		X
Robinson, Summers	2012	X	X				X	X	X	X	X					X	X		X
Heller, Coleman, Best, Emerson	2013	X	X				X		X	X	X	X	X	X	X		X	X	X
Heller, Coleman, Best, Emerson, Garrett	2014	X					X		X		X	X			X		X		
Brunt	2018			X	X		X		X		X				X		X	X	X
Robinson, Ekins, Durrant, Summers	2018	X	X	X			X		X						X				X

Table 4. Topics in the ScoRev literature focused on school staff (teachers and school nurses)

Author(s)	Year of publication	Relationship between the teacher and the child with LLC/LTC	Relationship between the teacher and the parents	Impact on the teacher's psyche/wellbeing	Teacher's support/coping strategies	Competences of the teacher/school staff	Teacher training	Teachers' readiness	Teachers' needs	Working with a class of children	Teachers' readiness for handling the topic of death in school
Papadatou, Metallinou, Hatzichristou, Pavlidi	2002a	X	X	X	X	X	X	X	X	X	
Stillion, Papadatou	2002										
Papadatou, Metallinou, Hatzichristou, Pavlidi	2002b			X		X	X	X	X	X	X
Rice, Gourley	2003				X	X				X	X
Seymour	2004										
Botcheva, Hill, Kane, Grites, Huffman	2004		X								
Munson, Hunt	2005			X	X	X	X	X	X		X
Asprey, Nash	2006	X	X					X			
Craig, Boden, Samuel	2012				X					X	
Robinson, Summers	2012	X	X	X	X	X	X	X	X		
Heller, Coleman, Best, Emerson	2013	X	X	X	X	X	X	X	X	X	X
Heller, Coleman, Best, Emerson, Garrett	2014	X			X	X		X	X		X
Brunt	2018	X	X	X	X	X		X	X	X	X
Robinson, Ekins, Durrant, Summers	2018	X	X	X	X	X			X	X	

pare future teachers for this crisis intervention (Franclová & Plachá, 2019).

Brunt (2018) emphasizes that teachers are not prepared to discuss the death of a child with their students. Most educators openly admit that they do not feel sufficiently competent to support their students and their family when they experience grief (Robinson et al., 2018). In this case, an alternative is close cooperation with the team of children's palliative care or children's hospice care who can accompany the bereaved through the entire process of loss (Heller et al., 2014; Ramer-Chrastek, 2000). Studies offer specific steps that teachers should take in the class in the case of the death of a child as well as advice for the preparation of the so-called death education (Heller et al., 2013; Rice & Gourley, 2003). A study by Munson and Hunt (2005) provides a brief guide on how to support oneself and colleagues in the event of a pupil's death.

It should be added that the analysis of the available literature meeting the predefined criteria showed some topics that had not been sufficiently elaborated including, for example, a child with LLC or LTC in the class, the relationship between children with LLC and LTC, and their classmates, the importance of education for children with LLC or LTC from their perspective. There is a lack of information concerning the education of children with LLC and LTC or their classmates.

Scoping Review Limitations

Table 1 shows that most of the papers identified in this ScoRev were published before 2010 (n=8). The education system and policy are constantly evolving including regular legislative changes, development of methodology, interventions, socio-economic conditions of individual countries (Feřtek, 2019) as well as progress in medicine and children's palliative care (Buřgová & Sikorová, 2019). This implies that some data obtained from the ScoRev literature may be outdated. The most recent knowledge from educational practice is presented only by two full texts: the dissertation (Brunt, 2018) and a journal article (Robinson et al., 2018). A more recent resource published after 2018 in accordance with the ScoRev criteria has not been identified.

Regarding the final number of the available relevant literature resources concerning the education of students LLC/LTC and with respect to the selected eligibility criteria for the selection of the ScoRev literature, the following hypotheses were proposed: (1) on a general basis, the education of students with LLC and/or LTC has not been thoroughly examined and there are no available re-

cent studies/literature on this topic, (2) there are a number of other studies on the topic that are searchable in databases but were not used for the ScoRev search, (3) there are other recent literature resources on the topic of education of children with LLC or LTC on a general basis but they use different terminology than LLC or LTC, for example, "terminal illness", "life-shortening illness", "chronic illness", "chronic conditions" and/or "chronic needs".

Assuming that there are no other available studies on the education of children and youth with LLC or LTC, we have encountered a research gap that signifies a lack of recent comprehensive knowledge on this type of education on a general basis. This provides space for further research the objective of which may be to map the current practice concerning the education of children and youth with LLC and LTC.

Conclusions and implications for research and practice

Given the findings of the ScoRev, further research should focus on the following: (1) identification of the methods of intervention that teachers use in the educational process to work with a group of students involving a child with LLC or LTC; (2) overview of the coping strategies that teachers use in the process of coping with the possibility of the death of a student in school; (3) identification of the role of children's palliative care and children's hospice care in the education of a child with LLC and/or LTC in practice; (4) analysis of the current multidisciplinary cooperation between the subjects involved in inclusive education of children with LLC or LTC.

A beneficial step forward in the research would be a review study which would map whether there are data on the opinions of children/youth with a specific LLC and LTC diagnosis concerning their education. Any research study should respect the evidence-based principle so that the findings are not only presented to the professional community but also used to fill gaps in practice.

CONCLUSION

As part of the ScoRev, a total of 13 journal articles and a dissertation relating to the education of children and youth with life-limiting and life-threatening conditions were identified in the available databases and synthesized. The most developed topics included the role of the teacher, challenges, and interventions in the education of a child with LLC and/or LTC. The education of students with LLC/LTC was most frequently examined from the

perspective of teachers in mainstream and special schools.

The final number of identified studies indicates a lack of available resources that reflect the current practice of educating children and youth with LLC and/or LTC on a general basis. Although the studies present significant information from educational practice, regarding the date of publication the information may be outdated. This provides space for further research on the state of the current practice and development of the topics that are crucial to the education of children and youth with LLC and LTC.

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