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Exploring pediatric palliative care in Luxembourg: a mixed-methods study

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Abstract

Background An estimated 170,000 children in the WHO European Region have no access to palliative care annually. In Luxembourg, there is a lack of data on children needing palliative care, and the existing structure appears limited. This study aims to assess the current state of pediatric palliative care in Luxembourg.

Methods We used a parallel convergent mixed-methods approach, collecting qualitative and quantitative data simultaneously and analyzing them independently. Snowball and purposive sampling methods were employed. The qualitative data, including documents, email correspondence, and open-ended interviews with participants caring for children with life-limiting or life-threatening conditions, followed the COREQ guidelines and were analyzed using thematic analysis. Quantitative data were analyzed using both descriptive and inferential statistical methods.

Results The analysis highlights a significant gap in the provision of care at all levels of pediatric palliative care in Luxembourg. Approximately 500 to 600 children up to 19 years old require palliative care each year, which exceeds previous estimates. Existing legal frameworks are predominantly designed for adults and end-of-life care, and do not sufficiently address the holistic needs of children requiring palliative care and their families. Homecare services are in the early development phase, and specialized pediatric palliative care options are limited across all levels. A pediatric palliative care course, set to be introduced in 2025 for university pediatric nursing students as outlined in the national plan, aims to address some of these gaps by developing competencies. However, until sufficient specialized care is established, many children are transferred to neighboring countries where there are better resources and expertise or remain at home, receiving limited services.

Conclusion This study presents, for the first time, data on pediatric palliative care in Luxembourg, with a focus on service availability, the legal framework, and the estimated number of children requiring care. The findings highlight the urgent need for a structured pediatric palliative care service to address this country's growing demand and unmet needs. In addition, it is essential to support the implementation of the “*National Plan for End of Life and Palliative Care*” from 2023 to 2026, which includes a dedicated focus on children.

Keywords Pediatric palliative care, Paediatric palliative care, Life-limiting conditions, Life-threatening conditions, Children, Palliative care services, Health policies, Luxembourg

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Introduction

The World Health Organization (WHO) defines pediatric palliative care as an approach that enhances the quality of life for children and families dealing with life-threatening illnesses [1]. Pediatric palliative care focuses on relieving suffering through the early identification, precise assessment, and treatment of pain and other symptoms, addressing physical, psychological, and spiritual dimensions [1]. The WHO acknowledges that palliative care is specifically identified as part of the human right to health [1]. Pediatric palliative care (PPC) is a distinct and specialized area within healthcare that is separate from, yet closely connected to, palliative care for adults [2]. It is estimated that globally, more than 21 million children annually may benefit from a palliative care approach, with over 8 million of these children requiring a specialized approach [3]. Each year, around 170,000 children in need of palliative care die in the WHO European Region [4, 5]. Ideally, assistance for children requiring palliative care should begin at the time of diagnosis, which for some children with life-threatening conditions may be at birth [2]. In certain cases, palliative care may be the only form of care provided, and this phase may last for an extended period. End-of-life care is just one aspect of pediatric palliative care [6]. Importantly, the early inclusion of pediatric palliative care does not mean the cessation of treatment aimed at curing or extending life [6]. PPC can be implemented concurrently or in parallel with these treatments [6, 7]. Thus, it is crucial to consider the advantages of combining PPC with other treatments. It can relieve symptoms, contribute to patient satisfaction and quality of life, decrease caregiver burden, potentially result in more appropriate referrals, decrease unnecessary use of intensive care, and possibly improve survival expectancy [7, 8].

Pediatric palliative care targets children and adolescents diagnosed with life-limiting and life-threatening conditions. In 1997, the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), in collaboration with the Royal College of Paediatrics and Child Health, published the first guide that formally defined pediatric palliative care and classified these conditions into four categories [9]:

- Group 1: Life-threatening conditions for which curative treatment may fail, such as cancer or irreversible organ failures.
- Group 2: Conditions where premature death is inevitable, with intensive treatment aimed at prolonging life, like cystic fibrosis or Duchenne muscular dystrophy.
- Group 3: Progressive conditions without curative treatment options, requiring long-

term palliative care, such as batten disease or mucopolysaccharidoses.

- Group 4: Irreversible but non-progressive conditions causing severe disability, leading to health complications and premature death, such as severe cerebral palsy or multiple disabilities post-injury.

A study conducted in England estimated an increasing number of children (0–19 years) living with a life-limiting condition (LLC) [10]. The numbers rose from 32 cases per 10,000 in 2009–2010 to 66.4 per 10,000 in 2017/2018, with a projected prevalence expected to reach 84.2 per 10,000 by 2030 [10]. The same study indicated that in 2017/2018, the highest prevalence was observed among children with congenital abnormalities, at 27.2 per 10,000, followed by neurological conditions at 10.8 per 10,000 [10]. Another national study in England estimated that approximately 86% of children with LLC are affected by non-oncological conditions [11].

Although these statistics underscore the growing need for pediatric palliative care, the development and accessibility of these services vary from one country to another. Understanding healthcare provision requires considering the national context. As of January 1, 2023, Luxembourg had a population of 660,809, an 81% increase since 1981 [12]. Despite a high per capita health expenditure of EUR 4,182, this only accounts for 5.7% of the Gross Domestic Product (GDP) [13]. The country operates a compulsory Social Health Insurance (SHI) system under the National Health Fund (*Caisse Nationale de Santé*, CNS), covering healthcare, sickness leave, and long-term care insurance [13].

Data on pediatric palliative care in Luxembourg is limited. According to the Atlas 2019, which provides a comprehensive overview of the development of pediatric palliative care on a national level across Europe, Luxembourg's National Pediatric Oncology and Palliative Care Services have been in development since 2017 [4]. Furthermore, the Atlas indicates that Luxembourg lacks inpatient hospices for children but does have one home program and one hospital program dedicated to pediatric palliative care [4, 5]. Moreover, the first regional assessment of pediatric palliative care (PPC) in 2020, revealed that Luxembourg reported no inclusion of PPC components in pediatric specialization training for medical doctors and nurses [5]. Additionally, there were no identified PPC specialized consultants, no specific national PPC association, and no established standards and norms for the provision of PPC [5].

However, beyond these documented reports on service provision, significant research gaps remain. There is a gap in the current literature regarding how the legal framework impacts pediatric palliative care services provision in Luxembourg. Additionally, there is limited

understanding of the availability of supportive services for children in need of palliative care and insufficient data on the number of children with life-limiting or life-threatening conditions in the country.

This study, therefore, aims to explore the current state of pediatric palliative care in Luxembourg and provide insights for future improvements in the field. The specific objectives of this research are as follows:

- To describe laws and policies shaping the implementation of pediatric palliative care services in Luxembourg.
- To explore the services and resources available for children needing palliative care in Luxembourg.
- To examine pediatric mortality and dependency cases in Luxembourg, by analyzing the causes and locations of pediatric deaths, as well as the main causes of dependency among children covered by long-term care insurance and their care locations.

Methods

Research design

This study employed a convergent mixed methods design to gather diverse yet complementary data on the phenomenon under investigation [14, 15]. The convergent design allows for the simultaneous collection of qualitative and quantitative data, with both given equal priority [14, 15]. This design is suited to research aiming to illustrate qualitative results with quantitative findings or vice versa [14, 15]. This approach follows the parallel database variant, wherein qualitative and quantitative data are analyzed separately and then combined for a comprehensive interpretation [15]. The qualitative phase followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [16]. The study was conducted as part of the primary investigator's doctoral research at the University of Luxembourg. The investigator holds a bachelor's degree in nursing and a master's in public health, with professional experience in the pediatric field that informed the research approach and facilitated effective engagement with participants.

Sampling and recruitment

For this study, we employed both snowball and purposive sampling techniques within an iterative approach to ensure a comprehensive and diverse participant pool [17]. We began snowball sampling by reaching out to participants with expertise and extensive networks, who referred us to other relevant professionals. In parallel, we used purposive sampling to directly select participants based on their specific expertise and roles in caring for children with life-limiting or life-threatening conditions.

We invited potential participants via email to take part in the study. Invitations were sent to eight physicians,

one nurse, eight home care networks, and 13 associations and non-profit organizations. Additionally, we contacted three individuals from academic institutions, specifically from the Medicine and Nursing Department at the University of Luxembourg. In the public sector, we contacted one person from the *Causes of Death Registry at the Health Directorate*, one person from the *National Social Security Fund's Palliative Department*, and two individuals from the Long-term Care Insurance, *General Inspectorate of Social Security* under the *Ministry of Health and Social Security*.

Due to the small size of Luxembourg and the close-knit nature of its healthcare community, most referrals consistently referred to the same physicians, associations, and home-care networks, suggesting recruitment saturation. This redundancy in referrals indicated that we had an adequate representative sample of professionals and institutions involved in caring for children with life-limiting or life-threatening conditions.

Data collection

For qualitative data, we conducted a review of documents, open-ended interviews, and email exchanges. Quantitative data was sourced from the *Causes of Death Registry at the Health Directorate* and the *Long-Term Care Insurance, General Inspectorate of Social Security under the Ministry of Health and Social Security* of Luxembourg. The qualitative and quantitative data were collected and processed simultaneously and independently [14], then integrated to gain a comprehensive understanding of pediatric palliative care services, associated legislation, and statistical insights.

The review of documents, often used alongside other qualitative research methods, complements mixed-methods studies by providing background information, context, and supplementary data while highlighting conditions influencing the phenomena under investigation [18].

To identify relevant documents for the qualitative phase, we adapted the grey literature search approach, which included: (i) targeted searches of governmental and organizational websites, (ii) customized Google searches to capture additional documents, and (iii) expert consultations to access non-published materials not available on the internet [19]. The review of documents covered Luxembourgish legislation on palliative and end-of-life care, official health reports, project reports, public sites, and online resources from non-profit organizations and home-care networks operating in Luxembourg.

The review of documents was accompanied by inquiries with participants to gain a deeper understanding of the available services and field practices. Out of 37 individuals contacted, 29 participated in the study. Most responded via email ($n=27$), with five of whom also

participated in open-ended interviews. One participant responded through a phone call. An overview of the participant groups, the number of individuals contacted and those who responded, as well as the formats through which information was provided, is presented in Table 1.

Participants were informed about the study's purpose, the importance of their participation, and the potential impact of the research on pediatric palliative care practice, policy, and service provision in Luxembourg. Interview questions (Appendix 1) were tailored to each participant's role and allowed flexibility to reflect individual experiences. The aim was to gather primary data and information on their services, experiences, and challenges in caring for children with life-threatening or life-limiting conditions in Luxembourg, including those in palliative or end-of-life care. Interviews lasted 30 to 60 min and were performed through videoconference, phone, or in person at the participant's workplace. When interviews were not possible, personalized questions were sent by email. Some interviews were audio-recorded with consent, and field notes were taken for all to capture key findings. All responses were transcribed verbatim and pseudonymized to ensure participant privacy.

We collected quantitative data from the *Causes of Death Registry at the Health Directorate*, which provided statistics on the number and causes of death among children. Due to the absence of a national disease registry in Luxembourg, we used secondary data on dependency cases among children from the *Long-term Care Insurance at the General Inspectorate of Social Security* as secondary sources. In this context, "dependency cases" refer to individuals of any age who require significant and regular assistance with daily activities due to illness or disability [20]. The state of dependency must be expected to remain unchanged for at least six months or be irreversible [20]. Qualitative and quantitative data collection were conducted simultaneously between January and May 2024.

Data analysis

We used thematic analysis to analyze the qualitative data from three sources: the review of documents, participant

responses received through email, and open-ended interviews. The quantitative data were analyzed using descriptive and inferential statistical methods.

Qualitative data analysis

Thematic analysis was used for the qualitative data, which included reviews of documents, open-ended interviews, and email responses. To ensure rigor and consistency, the thematic analysis adhered to Braun and Clarke's six-step process [21]. Thematic analysis was particularly suitable for processing data from the review of documents, as it involves coding and identifying patterns that integrate themes from multiple sources such as interviews and email responses [18]. Extracts, quotations, and passages from documents were organized under predefined categories which were used to identify themes [22]. Similarly, interviews and email response data were also analyzed using thematic analysis, integrating verbatim statements from participants to enrich the thematic analysis.

As a result, some themes incorporated data solely from the review of documents, others were specific to interviews and email responses, and some were shared across all three sources. The predefined categories were developed based on the study's objectives, ensuring alignment with the research aims. Manually coding was conducted using a deductive approach based on the study's objectives, with emergent themes from participants' interviews, responses to emails, and a review of documents incorporated to enhance a comprehensive understanding and exploration of the pediatric palliative care context in Luxembourg. Data saturation was reached when no new themes or insights emerged from subsequent interviews and responses [23].

The predefined categories were:

- Luxembourgish legal framework for palliative and end-of-life care.
- Associations and home care services for pediatric patients with life-limiting and life-threatening conditions.

Table 1 Participant groups, responses, and modes of participation

Participant Group	Contacted	Responded (questions through email)	Responded (open-ended Interviews)	Other Formats
Physicians	8	6	2	None
Nurse	1	N/A	1	None
Home Care Networks	8	6	None	None
Non-Profit Organizations	13	10	2	None
Academic Institutions	3	2	None	None
Causes of Death Registry	1	1	None	None
National Social Security Fund	1	N/A	None	1 (questions through phone)
Long-Term Care Insurance Department	2	2	None	None

- Academic and continuous education in pediatric palliative care.
- Financial support for palliative care.
- Insights from participants related to pediatric palliative care provision (e.g., physicians, nurses, public sector officials).

Quantitative data analysis

The quantitative analysis aimed to examine and illustrate pediatric mortality and dependency cases using secondary data [24] from the *Causes of Death Registry at the Health Directorate and the General Inspectorate of Social Security* under the Ministry of Health and Social Security in Luxembourg. The analysis focused on individuals aged 0 to 19 years, which is consistent with the WHO classification [25]. This age range was predefined by the respective ministries providing the data. In this study, “children” refers to neonates, infants, children, and adolescents from birth through 19 years of age [3]. This analysis directly addresses the third research objective, examining pediatric mortality and dependency cases. Descriptive and inferential statistical techniques were employed to analyze the data.

We used descriptive statistics to represent and explain the data, highlighting key aspects of pediatric dependency cases, care locations, primary causes of dependency, and mortality. To identify significant differences across categories, chi-square tests were used, while linear regression was applied to analyze trends over time.

Aggregated and pseudonymized data, ensuring confidentiality, were provided to a statistician for inferential statistical testing and visualization. Using Python, the statistician generated histograms, tables, and pie charts to clearly illustrate trends and category distributions. This analysis provided findings into the number of children with dependency cases under long-term care insurance who might benefit from a palliative care approach, along with their places of care, diagnoses, and places of death among children in Luxembourg.

Data cleaning

In our dataset, we encountered a few missing values, represented by indicators such as “<5,” for small values, or “<25,” “<30,” “<35,” for larger values that are overstated. Each row also includes total sums. Instead of simply deleting the corresponding rows, which would be inappropriate given the limitation of our dataset, we have chosen to utilize this information. Therefore, we systematically assigned an arbitrary value to the small values (typically 2 or 3) and calculated the missing values for the higher indicators using the total sums.

Ethical approval

This study was approved by the Ethics Review Panel of the University of Luxembourg reference number (ERP 23–106 EOLC). Either verbal or written informed consent was obtained from all participants for the use of the data they shared. Approval for secondary data use was granted by the *Causes of Death Registry at the Health Directorate and the General Inspectorate of Social Security* under the Ministry of Health and Social Security of Luxembourg. All collected data were pseudonymized to ensure confidentiality and to protect the privacy of participants and patients.

Results

This section presents the study’s findings, structured according to the three research objectives: describing the legal and regulatory context, exploring available services and resources, and examining pediatric dependency cases, care locations, and causes of death. The findings are organized into qualitative themes and presented alongside quantitative data.

To address the first objective, two main themes are presented: the legal framework for palliative care and the ongoing development of pediatric palliative care services. Both themes are derived solely from the review of documents.

Legal framework for palliative care in Luxembourg

Palliative care regulations in Luxembourg establish structured procedures to ensure standardized care provision, emphasizing the rights of individuals facing an incurable or severe illness in their final stage, with a particular focus on end-of-life.

The Law on palliative care, advance directives, and end-of-life care highlights the fundamental right to palliative care. Article 1 explicitly states: “Any person in the advanced or terminal phase of a serious and incurable illness, regardless of the cause, hereinafter referred to as ‘the person at the end of life,’ has access to palliative care” [26]. As outlined in the same chapter, palliative care is provided across hospitals, authorized healthcare facilities, and at home in compliance with the laws regulating health and long-term care insurance [26]. Another law, under Article 43 mandates that the hospital-attending physician must alleviate the physical and mental suffering of terminally ill patients and avoid ‘hopeless therapeutic relentlessness’ [27].

The regulation outlining the procedures for granting the right to palliative care defines both the initiation and the duration of this entitlement. Article 3 states that: “The declaration is validated by the *Contrôle médical de la sécurité sociale (Medical Control of Social Security)*”. Regarding the duration of this right Article 4 stipulates: “The right to palliative care expires within thirty-five days

from the date of its opening. Exceptionally, the right may be extended for one or more additional periods of thirty-five days, on the duly motivated initiative of the attending physician(s) “ [28].

In parallel, another regulation establishes the format and content specifications for the care booklet used in end-of-life palliative care. Article 1 defines the care booklet as: “a tool for liaison, communication and coordination”. In addition, Article 4 specifies: “The care booklet is always available to the person being cared for and accompanies them to all the places where they are staying” [29].

Developing pediatric palliative care in Luxembourg

To address the unique needs of children requiring palliative care, Luxembourg incorporated a dedicated focus on pediatric palliative care into the *Plan National Fin de Vie et Soins Palliatifs 2023–2026 (National Plan for End-of-Life and Palliative Care 2023–2026)* [30], thereby building on the measures introduced in the *Plan National Cancer Luxembourg 2014–2018 (National Cancer Plan Luxembourg 2014–2018)* [31].

The *National Cancer Plan Luxembourg 2014–2018* [31] primarily focused on children with cancer, aiming to implement end-of-life care integrated into the National pediatric hematology oncology sector (*Secteur national d'onco-hématologie pédiatrique*). Notably, Axis 6, titled *Cancer Treatment and Supportive Care*, and specifically Action 6.3.5, emphasized “implementing appropriate end-of-life care for children” [31]. As part of this plan, a *Concept de soins palliatifs pédiatriques (Concept for pediatric palliative care)* [32] was validated in 2015, highlighting the need and plan for a structured, coordinated approach to pediatric end-of-life care for both oncological and non-oncological conditions. This concept addressed the role of the multidisciplinary team in delivering comprehensive end-of-life care for children and their families in various settings, including hospitals, homes, and respite facilities. The concept also reported that “an estimated 8 to 10 children with cancer require

end-of-life care annually, while approximately 40 to 50 children across all pathologies need pediatric palliative care each year [32]. Furthermore, “between 16 and 18 children aged 0 to 18 die each year in Luxembourg from various pathologies and require pediatric palliative care” [32]. However, as reported in the *National Plan for End-of-Life and Palliative Care 2023–2026* “this concept has not yet been implemented and requires updating” [30].

While the *Concept for Pediatric Palliative Care* placed the groundwork for structured pediatric end-of-life care, the *National Plan for End-of-Life and Palliative Care 2023–2026* introduces a dedicated axis for pediatric palliative care with four objectives: Organizing pediatric palliative care, providing training in pediatric palliative care, addressing the issue of euthanasia and assisted suicide in minors, and establishing of a respite care structure for children in palliative care and their families [30]. To support these objectives, the plan outlines specific measures and actions, summarized in Table 2.

To address the second objective, findings related to the services and resources available for children needing a palliative care approach in Luxembourg are presented below. These findings are presented according to key themes: challenges in homecare and hospital settings (from open-ended interviews and email responses), support systems for families, financial support, and the availability of academic and continuous education for healthcare providers (from review of documents, interviews, and email responses).

Challenges in home care and hospitals
Homecare challenges in pediatric palliative care

Most participants reported that providing care for children with life-limiting and life-threatening conditions, or children in end-of-life, is particularly challenging for homecare networks in Luxembourg. Responses gathered from these networks reveal that PPC provision remains limited, primarily due to a lack of specialized pediatric

Table 2 Key measures and actions in Axis 4 of the 2023–2026 National palliative care plan

National Plan for End-of-Life and Palliative Care 2023–2026. Axis 4: “Creating an offer for minors”	Objective 4.1: “Organize pediatric palliative care”.	Objective 4.2: “Provide training in pediatric palliative care”.	Objective 4.3: “Address the issue of euthanasia and assisted suicide in minors”.	Objective 4.4: “Establishment of a respite care structure”.
Key measures and actions	Measure 4.1.1: “Establish a hospital-based and mobile expert pediatric palliative care (PPC) team and outline its operational framework as a PPC concept in Luxembourg, integrating all stakeholders necessary for holistic care” [30]. Action 4.1.1.2: “Ensure long-term support. Pediatric palliative care (PPC) can sometimes begin at the diagnosis of a severe condition, which may occur at birth or even before the child’s birth” [30].	Measure 4.2.3: “Create a pediatric palliative care training program in Luxembourg, open to all healthcare professionals” [30].	Measure 4.3.2: “Adapt the legal framework to clarify the specific situation regarding medical futility and euthanasia for minors” [30]. Action 4.3.2.3: “Provide families with the option of psychological support in cases of bereavement” [30].	Measure 4.4.1: “Adapt the legal framework to support the establishment of a respite care facility” [30].

nurses, and limited staff training in PPC within the network teams.

Few networks reported that they do not provide PPC services and primarily serve elderly patients indicating the absence of pediatric nurses as a key obstacle. As one network stated:

"We do not provide care for pediatric palliative patients; we only have elderlies. We do not have pediatric nurses within our network, so it is difficult for us to take on pediatric cases" (HC1).

Few networks reported that they receive very few requests for PPC services.

"We offer care for children in palliative care, but we only receive very few requests per year" (HC3).

Despite these challenges, some networks have started to accept pediatric cases, with staff receiving general palliative care training and relying on the expertise of nurses trained in palliative care abroad. One network stated:

"Recently started accepting pediatric cases. Staff will receive training in general palliative care, and there are nurses already trained in France" (HC5).

Another network detailed its provision of PPC through collaborations with hospitals and trained nursing staff in general palliative care. Some involve adolescent children with neurological conditions that were followed for several years, whereas others include newborns and infants requiring shorter-term support. One network representative stated:

"The Network allows beneficiaries of all ages to receive palliative care at home. We actively collaborate with hospitals, with which we have agreements for various nursing and support services. Over the last 5–6 years, we have had a few cases, though they remain occasional. The most significant involved adolescents with neurological disease, who were supported by the network for 4 to 5 years. For some others, particularly infants of few months old 2 or 3 months. These were shorter-term cases, lasting a few days or weeks at most, for even more severe conditions" (HC6). "We have nurses with experience working with children of all ages, trained in general palliative care, as well as internal palliative care trainers" (HC6).

Challenges in accessing pediatricians trained in PPC for home-based interventions were also highlighted. Professionals described this gap as particularly difficult when

managing complex end-of-life situations at home. One respondent shared an example that illustrates both the dedication of providers and the structural limitations they face:

"There are currently no private pediatricians trained in pediatric palliative care who could intervene at home; only a few are available, and they work exclusively in hospitals. In one case, the attending physician at the hospital coordinated with the homecare network to follow a child at the end of life, managing medication and care. However, the physician was not part of the network nor financially compensated for their involvement... This was done voluntarily for the benefit of the child, as there is currently no expertise available to manage such complex cases at home" (HC8).

Despite these challenges, several healthcare professionals shared that some families often prefer to keep their children at home during the end-of-life phase or while managing chronic and complex conditions to remain close to loved ones in a familiar environment. One professional noted:

"...many families often want their child to stay in their environment, close to the family and in the comfort of home" (HC8).

Hospital challenges in pediatric palliative care

Hospitals in Luxembourg, primarily the *Centre Hospitalier de Luxembourg* (CHL), serve as the main setting for providing care to children, particularly those requiring specialized interventions, continual medical care, or support during end-of-life or palliative care. However, there are currently no in-patient beds specifically dedicated to pediatric palliative care. The location of care delivery within the hospital is primarily determined by the child's health condition as stated:

"Children with serious conditions, including those in the terminal phase of cancer, can receive care in the general pediatric ward or the intensive care unit at CHL KannerKlinik. This choice depends on their medical condition" (HC18).

However, it was reported that the limited availability of specialized pediatric care in Luxembourg poses significant challenges. Healthcare professionals expressed concern that, due to this lack of local expertise and resources, children with complex needs are often transferred to neighboring countries for more advanced care. This arrangement can be logistically and emotionally burdensome for families. As one professional explained:

“...children are sometimes transferred to neighboring countries, like Belgium, Germany, or France, where greater expertise and resources to support complex cases” (HC8).

One Healthcare professional reported that some families prefer their child to remain in the hospital during the terminal phase of their illness, expressing that they feel unprepared to manage end-of-life care at home:

“Some families are afraid of having their child pass away at home, so they prefer to be in the hospital instead” (HC17).

On the other hand, hospital staff face emotional challenges, particularly when a child passes away in the ward:

“When a death occurs on the ward in the hospital, it’s a major trauma for the nurses” (HC16).

Separately, it was reported that there is a shortage of nurses specialized in pediatric palliative care at the hospital level which limits the ability to provide comprehensive care for children with serious conditions.

Support systems for families and children in palliative care

Organizations and associations in Luxembourg were perceived to play a crucial role in supporting families and children with illnesses, including those under palliative care. These services include psychosocial and emotional support, managing socio-administrative and logistical procedures, and helping families and children cope with the challenges of serious health conditions. Some associations maintain their support throughout the entire journey, from diagnosis and treatment to recovery and end-of-life care.

“We accompany families from the diagnosis stage until the children are either survivors or, in some cases, receive palliative care” (HC12).

It was noted by one association supporting children with cancer that families often choose to return to Luxembourg during the palliative stage to reduce the burden on the family and stay closer to home:

“Often, at the palliative stage, children are referred to doctors in Luxembourg to reduce travel distances and make trips shorter” (HC12).

Some associations provide support for parents and siblings following the death of the child, highlighting the essential role of grief support. One association shared:

“Supporting parents and siblings when a child passes away is part of our work. We also provide support during the end-of-life phase if the family wishes” (HC10).

Another association in Luxembourg specializes in perinatal grief, offering tailored support as stated:

“We offer support for parents through phone calls, text messages, or support groups... About every two months, we hold a two-hour group meeting for parents who have lost a child. This allows them to talk and share their feelings with others who, unfortunately, have experienced a similar loss” (HC13).

Interviewed healthcare professionals emphasized the challenges faced by families caring for children with serious conditions, expressing concern over the lack of specialized facilities and services, including night care and respite services, to ease their burden. One professional stated:

“There is no facility to accommodate children with palliative care needs, and there is also no night care available to give parents respite and provide a temporary place for their children to stay” (HC17).

Families in Luxembourg can access additional support through legal provisions. These measures include specific leave and services to assist parents and caregivers during critical periods of their child’s illness. One such provision is accompanying leave [26], which is outlined in Article 9 of the Law on *Palliative Care, Advance Directives, and End-of-Life Support*. This law allows employees to take time off work to accompany a first- or second-degree relative in the terminal phase of their illness. The leave is limited to five working days (or 40 h) per dying relative per year and ends upon the death of the individual [26].

Family leave for a child’s illness [33] provides another support when no alternative childcare options are available, with durations determined by the child’s age:

- 12 days for children aged 0 to less than 4 years old;
- 18 days for children aged 4 to less than 13 years old;
- 5 days for children aged 13 to 18 years old, but only in cases of hospitalization [33].

In certain cases, the leave can be extended if the child has a progressive form of cancer, requires hospitalization for more than two weeks, or is placed in quarantine, the leave can be extended by up to 52 weeks [33]. Both parents can take this leave, although not simultaneously [33].

Another form of support is night supervision [34]. As outlined in the Regulation on Dependency

Determination (Article 8, Annex 2): “*The service of night care involves the overnight supervision of a dependent individual in their home, requiring the presence of a third party around twenty-four hours a day. This service allows for the temporary replacement of a caregiver in cases of short-term absence, the need for respite, hospitalization, or permanent unavailability. An annual allowance of 10 nights is provided*” [34].

Limited access to financial support in pediatric palliative care

The funding for palliative care in Luxembourg applies to both adults and children. However, the current legislation in Luxembourg only considers terminal palliative care within the legal framework for palliative care [32]. Access to palliative care requires a declaration by the attending physician to the *Medical Control of Social Security*. Upon approval, the *National Health Fund* issues a care entitlement document, granting access to covered services such as medical care, consultations, and, where applicable, out-of-hospital palliative care defined by CNS rules and relevant nomenclatures [35].

It was stipulated in The Law of March 16, 2009, on palliative care, advance directives, and end-of-life support states in Article 1: “*Palliative care is provided in hospitals, in approved facilities by health and long-term care insurance laws, or at home. For individuals receiving care at home or in care and aid institutions, close collaboration with a hospital is ensured. The provision of supplies, procedures, and services by various categories of providers involved in the patient's care is documented in a care booklet*” [26].

In parallel, long-term care insurance helps cover the costs associated with assistance for dependent individuals regardless of age, whether at home or in care facilities. This includes benefits in kind, support for assistive technology, and home adaptations, with an option for cash benefits under certain conditions [20]. When a person is granted palliative care, the strict evaluation and review procedures of long-term care insurance are waived [36]. This entitlement allows access to support for essential activities of daily living, including personal hygiene, nutrition, and mobility, tailored to the individual's needs and within legal limits [36]. A flat-rate allowance of 780 min is applied for essential activities of daily living [36]. Beneficiaries already receiving cash benefits under long-term care insurance continue to receive them upon approval of their palliative care entitlement [36].

To address the dependency needs of children up to 8 years old, long-term care insurance evaluates young children up to 8 years old by comparing their additional requirements to those of a healthy peer [20]. As stated by the long-term care insurance (2024) “*All young children need their parents' help to perform activities of daily*

living. Some children, however, as a result of illness or disability, need more help with activities of daily living than others. [20]”.

However, professionals emphasized the limited coverage for children under 2 years old with life-limiting or life-threatening conditions as a significant challenge and a concerning gap that limits their ability to fully support the youngest patients. As one professional explained:

“Dependency insurance rarely covers children under 2 years old with serious conditions because, according to them, parents are expected to care for their children at that age” (HC17).

Additionally, patients receiving palliative care are required to pay for certain costs not covered by Social Security [35]. The principle of patient financial participation under the health insurance system applies to specific services, such as partial reimbursement for medical consultations [35]. Service providers are required to inform patients about any amounts they must cover themselves [35].

The interviewed professionals pointed out that the lack of financial agreements not only limits care delivery but also clashes with their sense of duty to support children and their families beyond the hospital, as one healthcare professional explained:

“Right now, we don't have any pediatricians trained in pediatric palliative care who can provide care at home... The few who are trained have to work exclusively in hospitals, and with the absence of a budget agreement, hospitals can't currently provide care and visits at home.” (HC8).

Academic and continuous education in pediatric palliative care

Under the *Law of palliative care, advance directives, and end-of-life support* [26] Article 1 states: “*The State ensures the appropriate training of medical and nursing personnel. A grand-ducal regulation determines the organization of specific medical training in palliative care for physicians and other healthcare professionals.*”

The *National Plan for End of Life and Palliative Care 2023–2026* [30], under Axis 4, titled “*Creating an Offer for Minors*” includes Objective 4.2: “*Provide Training in Pediatric Palliative Care*”. This objective aims to enhance pediatric palliative care provision through targeted training initiatives. Plans include incorporating a pediatric pain management module and integrating training on child death and bereavement into the nursing pediatric specialization curriculum at the University of Luxembourg [30]. Additionally, a continuing training program

on PPC will be developed, accessible to all healthcare professionals in Luxembourg [30].

The development of a 40-hour Pediatric Palliative Care course for Bachelor of Nursing Science students specializing in pediatrics at the University of Luxembourg began in 2023. This course, which will be officially offered starting in 2025, marks the first inclusion of pediatric palliative care in undergraduate nursing studies in Luxembourg. This course includes, but is not limited to, the nursing approach to children with complex chronic diseases or those requiring perinatal and pediatric palliative care, pain and severe symptom management in pediatric palliative care, cultural considerations, grief support for families and siblings coping with loss, and respite care services.

In contrast, the Bachelor of Medicine curriculum does not currently include pediatric palliative care. Instead, it focuses on palliative care for adults and the elderly, covering themes such as supportive care, pain management, end-of-life care, and euthanasia.

Continuous education in palliative care in Luxembourg is organized under the Regulation on the organization of training in palliative and end-of-life care, issued on 8 February 2019 [37]. This training primarily focuses on palliative care for adults and the elderly. It defines three levels of education organized by skill level, applicable to physicians, other health professionals, and staff in care services for the elderly.

Most homecare network staff receive general palliative care training, mainly delivered by the Luxembourgish association *Omega 90*, in alignment with this regulation.

In contrast, pediatric staff in hospital wards lack specific training in pediatric palliative care. Educational opportunities in this specialized field are limited, with some sessions offered through hospital conferences or provided by non-profit organizations. One participant noted:

"We assist and support healthcare professionals by organizing training sessions on perinatal bereavement and addressing their questions and concerns" (HC13).

Quantitative data

To address the third objective, this section begins by analyzing pediatric mortality, including causes of death, death locations, and trends over time. It then presents findings on dependency cases, care locations, and contributing factors for children under long-term care insurance.

An overview of pediatric mortality causes and trends in Luxembourg

From 2001 to 2022, an analysis of 722 deaths among the pediatric population aged 0–19 years in Luxembourg revealed that external causes of morbidity and mortality (31.9%)—including accidents and intentional injuries—and perinatal conditions (30.7%) were the leading causes of death, together accounting for over 62% of cases. Other significant contributors included congenital malformations and chromosomal abnormalities, which contributed to 10.8% of deaths, highlighting the role of genetic factors in pediatric mortality. Neoplasms (5.8%) and nervous system disorders (5.3%) were less frequent causes; however, they remain significant causes of death, highlighting the impact of pediatric cancers and neurological conditions on mortality in this population (Fig. 1).

To better understand mortality patterns beyond the infant period, which refers to the first year of life, a subset analysis was conducted on pediatric deaths among children and adolescents aged 1–19 years. This group (1–19 years) was extracted from the total cohort of pediatric deaths (0–19 years, $n=722$), resulting in a subset of 358 cases. The majority of these cases (61.2%) were caused by external factors, including accidents and other incidents, making them the leading cause of death in this age group. Neoplasms were reported for 11.4% of deaths, making them the second most common cause and highlighting the impact of pediatric cancers. Other significant contributors included neurological disorders (6.1%), congenital malformations and chromosomal abnormalities (5.6%), and heart and circulatory diseases (4.8%), representing a significant portion of overall child and adolescent mortality. (Fig. 2)

Among children aged 0–19 years in Luxembourg from 2001 to 2022, males were consistently more represented across most causes of death compared to females. The leading causes of mortality were external causes of morbidity and mortality and perinatal conditions accounted for a significant number of deaths, with 128 cases among males and 94 among females, highlighting a marked predominance in males. Moderate contributors included congenital malformations and chromosomal abnormalities and neoplasms, with a greater number of male deaths. Additionally, nervous system disorders with 25 male deaths compared to 13 female deaths, also demonstrated a higher male representation. While endocrine, nutritional, and metabolic disorders showed a slight predominance of female deaths (Fig. 3).

Table 3 summarizes trends in deaths among children aged 0–19 years in Luxembourg from 2001 to 2022, categorized by ICD-10 chapters. Significant decreases were observed in general symptoms and abnormal findings ($p=0.00$, $R^2=0.442$) and external causes of morbidity and mortality ($p=0.01$, $R^2=0.299$). Conversely, upward

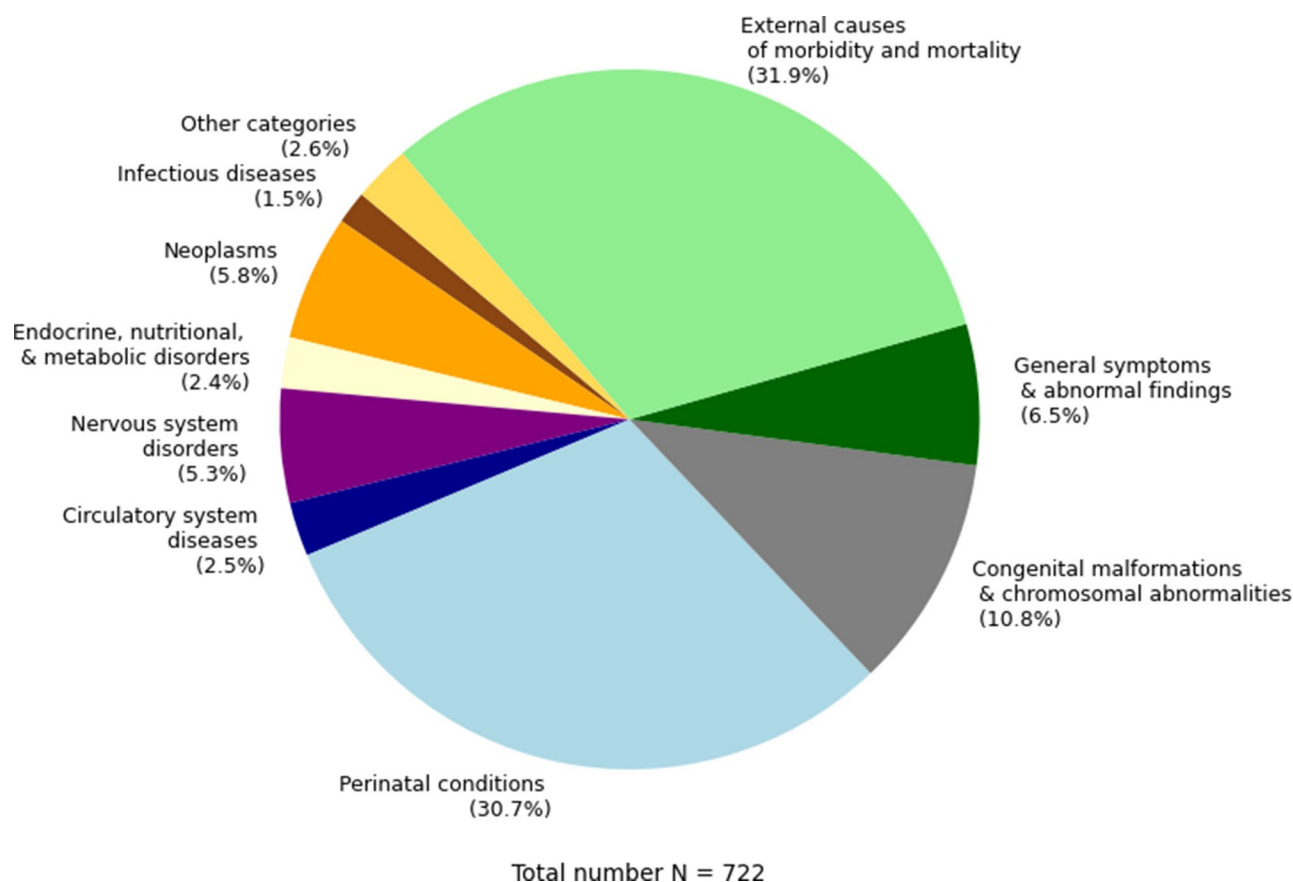


Fig. 1 Cause Of Death Distribution Among Pediatric Population (0–19 Years) In Luxembourg, 2001–2022. Original data from: Health Directorate. Causes of Death Registry. Luxembourg, February 2024. Note: These figures include deaths of both residents and non-residents occurring within Luxembourg. Stillbirths are excluded from these statistics

trends were noted in categories such as neoplasms, perinatal conditions, congenital malformations and chromosomal abnormalities, while these changes were not statistically significant.

The majority of deaths due to disease occurred in hospitals, consistently representing the largest proportion across all years, particularly among infants (0-year-old category). Hospital deaths accounted for 81.45% of all disease-related deaths during this period, making hospitals the primary place of death in pediatric and infant mortality. Deaths at home represented 16.88%, indicating a smaller but stable proportion over time, while deaths in other locations were rare, comprising only 1.67% of the total and showing minimal variation over the years (Fig. 4).

Analysis of pediatric dependency cases under Long-Term care insurance in Luxembourg

The data illustrate the 20 principal causes of dependency among individuals under 20 years of age who benefit from long-term care insurance in Luxembourg in 2023, categorized by sex. This information is not exhaustive, as it reflects only individuals registered under long-term

care insurance. Males are more represented across conditions, including pervasive developmental disorders (408 males vs. 106 females), lack of expected normal physiological development in childhood (23 males vs. 11 females), primary disorders of muscles (19 males vs. 2 females), and microcephaly (10 males vs. 5 females). Some conditions, such as Down syndrome (61 males vs. 54 females) and cerebral palsy (51 males vs. 45 females), show a more balanced distribution between sexes, although males still slightly outnumber females. Conversely, monosomies and deletions from the autosomes show a higher presence in females compared to males (15 females vs. 10 males) (Fig. 5).

Place of care for children with dependency cases under Long-Term care insurance

Between 2020 and 2023, the number of children under 20 years of age benefiting from long-term care insurance in Luxembourg increased by 22.7%, from 1,319 in 2020 to 1,618 in 2023. These numbers are cumulative, including children who remain in the system across multiple years and newly enrolled cases each year. The majority of children with dependency cases reside exclusively at

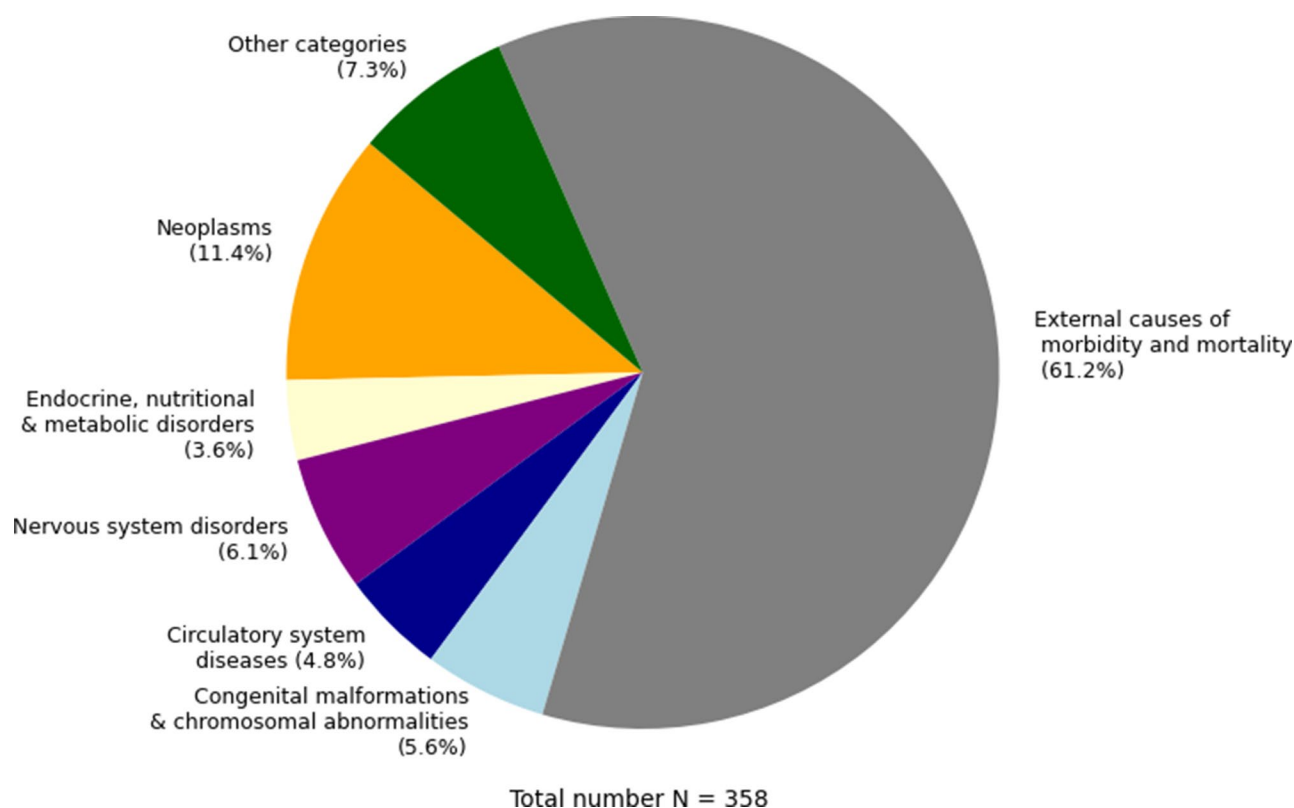


Fig. 2 Cause Of Death Distribution Among Pediatric Population (1–19 Years) In Luxembourg, 2001–2022. Original data from: Health Directorate. Causes of Death Registry, Luxembourg, February 2024. Note: These figures include deaths of both residents and non-residents occurring within Luxembourg. Stillbirths are excluded from these statistics

home, representing 93.3% of the total in 2020 and 93.5% in 2023. The number of children cared for solely at home increased from 1,231 in 2020 to 1,513 in 2023.

In contrast, the proportion of children receiving care in Intermittent Stay and Care Establishments (*Établissement d'aides et de soins à séjour intermittent*, ESI) or through a combination of home and ESI has remained small and consistent over the years. Children aged 5–9 and 10–14 consistently represented the largest age groups under long-term care insurance across all years. For instance, in 2023, 490 children aged 5–9 and 451 children aged 10–14 were covered, compared to 266 in the 0–4 age group and 306 in the 15–19 age group. Adolescents (15–19 years) had a higher representation in ESI and a combination of home and ESI as their place of care, compared to younger age groups (Fig. 6).

The results of the Chi-square tests presented in Table 4 demonstrate a statistically significant association between age group and place of care across all years (2020–2023), with χ^2 values increasing from 27.00 in 2020 ($p = 0.0001$) to 56.29 in 2023 ($p < 0.0001$). These findings indicate significant variability in the distribution of children across the three places of care (home, ESI, and combined home and ESI) by age group.

In each year, younger children (0–4 years) were predominantly cared for at home, with negligible representation in ESI or combined home and ESI settings. For instance, in 2023, 266 out of 268 children aged 0–4 years were cared for at home. By contrast, adolescents (15–19 years) consistently showed higher proportions in ESI and combined home and ESI settings compared to younger age groups. For example, in 2023, 38 out of 353 adolescents (15–19 years) were in combined care, and 9 were exclusively in ESI. This consistent pattern over the years highlights that younger children were overwhelmingly cared for at home, while adolescents were more likely to receive care in ESI or combined home and ESI settings (Table 4).

The p-value of the linear regression ($p < 0.05$) indicates a statistically significant upward trend in the number of children under long-term care insurance exclusively cared for at home from 2020 to 2023. The slope (95.8) reflects an average annual increase of nearly 96 children receiving care at home. Additionally, the R^2 value (0.99) confirms that the model accounts for almost all variance in the data, highlighting a strong linear relationship over the observed years (Table 5).

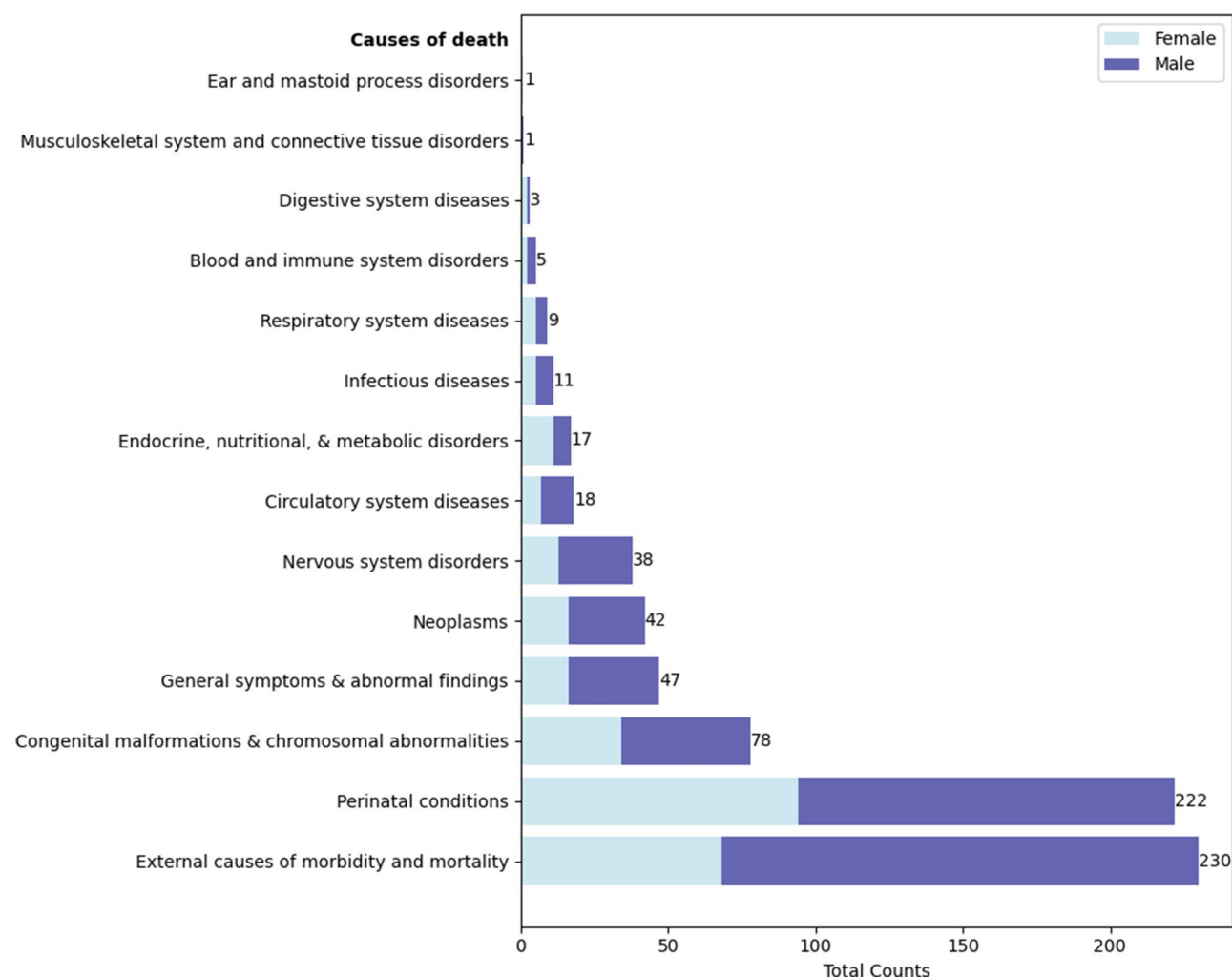


Fig. 3 Death Causes by Sex Distribution in Pediatric Population (0–19 Years), Luxembourg, 2001–2022. Original data from: Health Directorate. Causes of Death Registry. Luxembourg, February 2024. Note: These figures include deaths of both residents and non-residents occurring within Luxembourg. Stillbirths are excluded from these statistics

Table 3 Trends in causes of death among children (0–19 Years) in Luxembourg (2001–2022)

Chapter	Slope	p-value	R ²	Trend	Significant at 95%
Infectious diseases	-0.012	0.64	0.011	Decrease	No
Neoplasms	0.038	0.27	0.06	Increase	No
Blood and immune system disorders	-0.003	0.87	0.001	Decrease	No
Endocrine, nutritional & metabolic disorders	-0.007	0.78	0.004	Decrease	No
Nervous system diseases	-0.105	0.07	0.151	Decrease	No
Ear and mastoid process disorders	0.001	0.19	0.085	Increase	No
Circulatory system diseases	-0.0576	0.14	0.108	Decrease	No
Respiratory system diseases	-0.014	0.54	0.019	Decrease	No
Digestive system diseases	-0.016	0.17	0.092	Decrease	No
Musculoskeletal system and connective tissue disorders	-0.006	0.4	0.036	Decrease	No
Perinatal conditions	0.097	0.36	0.041	Increase	No
Congenital malformations & chromosomal abnormalities	0.031	0.67	0.009	Increase	No
General symptoms & abnormal findings	-0.19	0.00	0.442	Decrease	Yes
External causes of morbidity and mortality	-0.379	0.01	0.299	Decrease	Yes

Original data from: Health Directorate. Causes of Death Registry. Luxembourg, February 2024

Note: These figures include deaths of both residents and non-residents occurring within Luxembourg. Stillbirths are excluded from these statistics

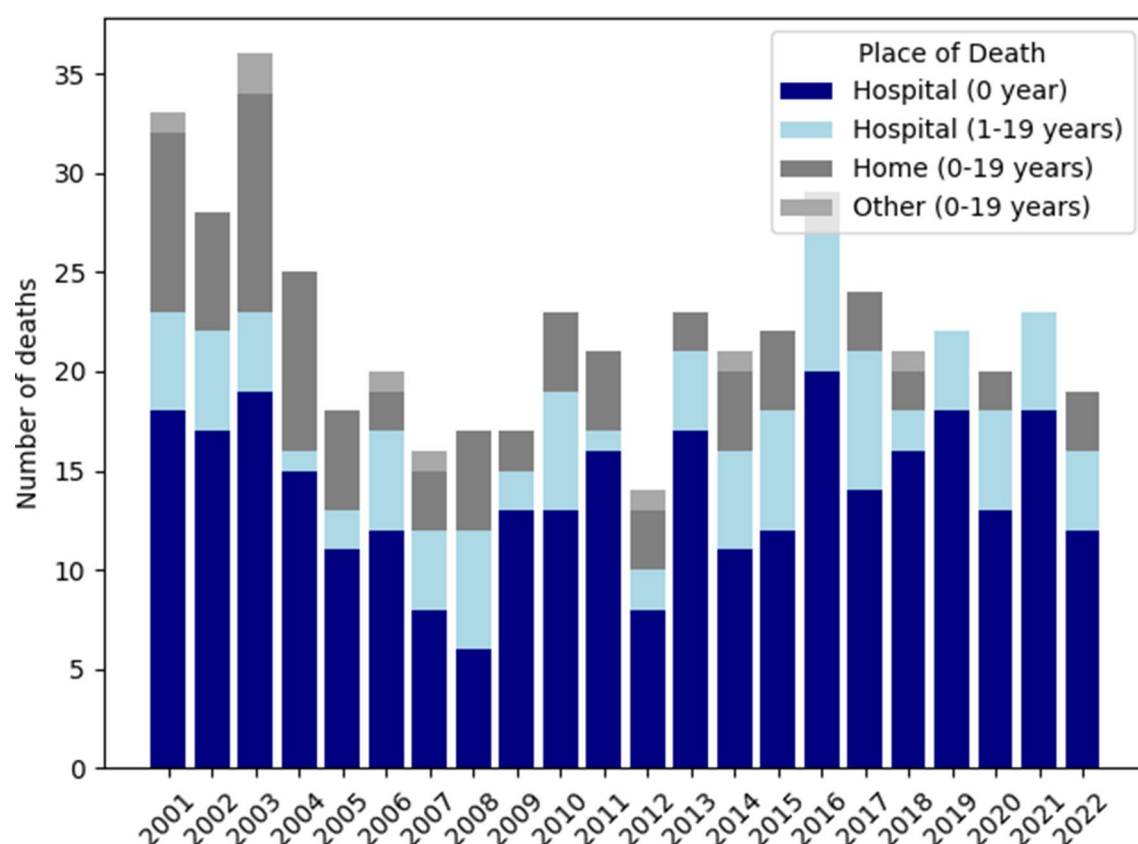


Fig. 4 Place and Number of Deaths in Pediatric Population (0–19 Years), Luxembourg, 2001–2022. Original data from: Health Directorate. Causes of Death Registry. Luxembourg, February 2024. Note: These figures include deaths of both residents and non-residents occurring within Luxembourg. Stillbirths are excluded from these statistics

Palliative care entitlement among children covered by Long-Term care insurance (2020–2023)

Between 2020 and 2023, only 5 children received the palliative care entitlement in Luxembourg. All these children passed away within the same year the entitlement was issued.

Estimation of the number of children requiring pediatric palliative care in Luxembourg

Approximately 500 to 600 children up to 19 years old in Luxembourg may require a pediatric palliative care approach, based on the analysis of long-term care insurance data and mortality figures. In 2023, a total of 1,618 children were covered under Luxembourg's long-term care insurance system, of whom 1,330 children were represented under the most common dependency causes (Fig. 5).

From this dataset, 737 children were identified as not falling under pediatric palliative care categories, while 319 children were confirmed to meet palliative care eligibility criteria based on their diagnoses. Additionally, 274 children had conditions that may require palliative care but need further assessment, as eligibility is determined

not only by diagnosis but also by associated morbidities and the child's specific medical needs.

Beyond these identified cases, several additional factors contribute to the estimated 500–600 children requiring palliative care. Among the 288 children remaining from 1,618 in the total dataset who were not classified under the most common dependency causes, various diagnoses appeared across different ICD-10 chapters, with small case numbers in each category. Among the 288 cases, approximately 15 children with cancer were registered under the long-term care insurance. Furthermore, in 2023, five children were granted palliative care entitlement, reflecting a small but important number of the population. In addition, the long-term care insurance system does not comprehensively cover children under the age of two with life-limiting or life-threatening conditions, contributing to uncertainty in the real number of cases. Moreover, children transferred abroad for specialized treatment are not always accounted for if they are not registered under the long-term care insurance. Similarly, children who are not yet registered or never registered under Luxembourg's long-term care insurance remain unaccounted for in the available figures. The mortality figures used in this estimation only

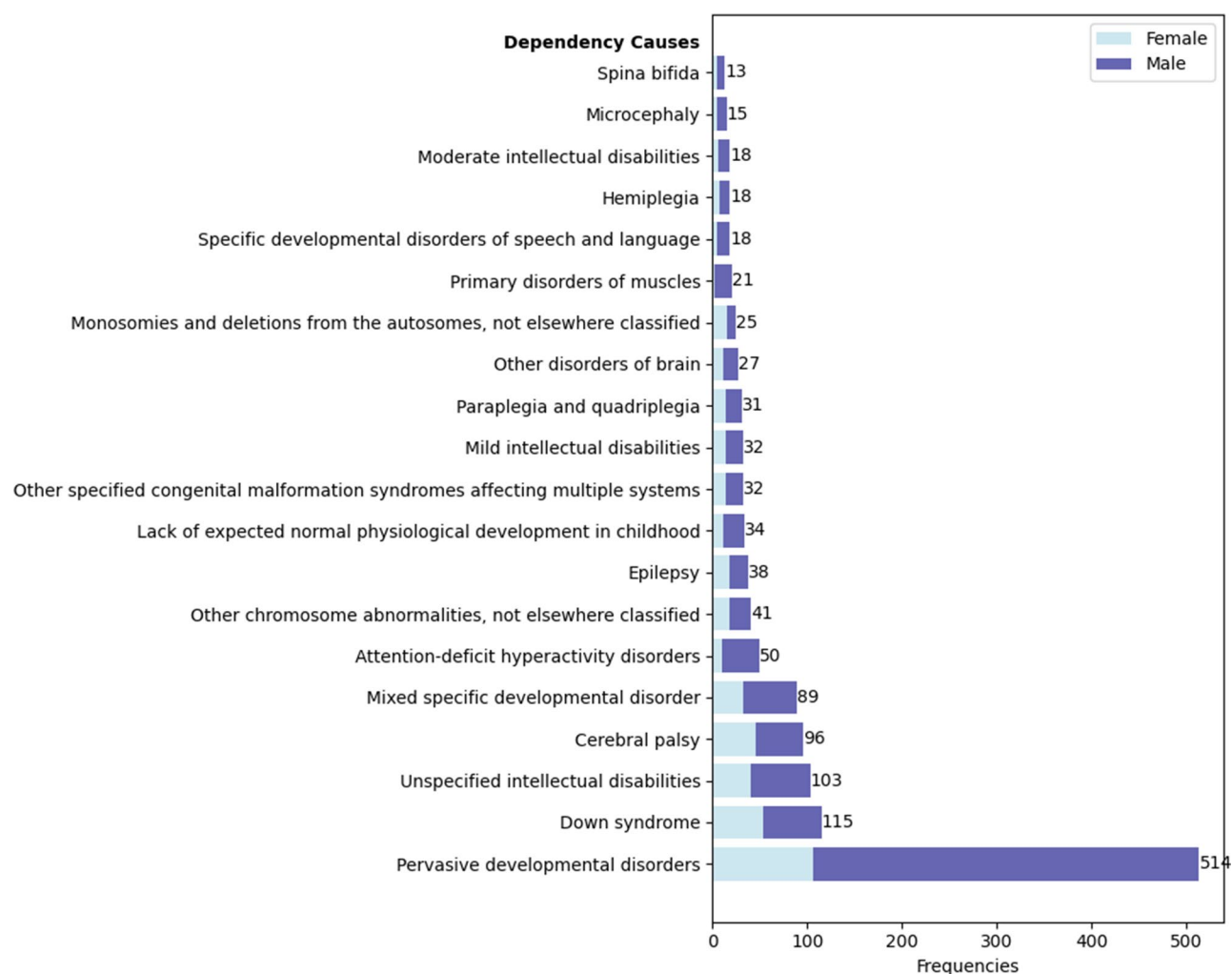


Fig. 5 Most Common Causes of Dependency in Children (0–19 Years) Under Long-Term Care Insurance, Luxembourg, 2023. Original data from: The government of the Grand Duchy of Luxembourg, Ministry of Health and Social Security. General Inspectorate of Social Security. (April 2024). Note: The statistics include individuals under 20 years old benefitting from a care summary under Luxembourg's long-term care insurance. This includes individuals affiliated with Luxembourg's health and maternity insurance, both residents and non-residents, and individuals receiving long-term care insurance benefits in Luxembourg under an international agreement

include decedents or children who passed away from various conditions requiring palliative or end-of-life care. However, non-decedents, or children with serious conditions requiring palliative care who remain alive and are not covered under long-term care insurance, also contribute to the overall estimation. Considering these data and factors, the estimated 500 to 600 children requiring pediatric palliative care annually in Luxembourg is based on confirmed cases, cases requiring further assessment, and unaccounted populations that are likely to fall under pediatric palliative care categories.

Discussion

This mixed-methods study integrates qualitative sources and national statistical data to examine pediatric palliative care in Luxembourg. Following the convergent design, specifically the parallel databases variant, both

data types were brought together in the discussion to enable an overall interpretation. This complementary integration allowed for a multidimensional understanding across all three objectives: examining the legislative and regulation framework, exploring the availability of services and resources, including the challenges that healthcare professionals face in homecare and hospital settings, and analyzing pediatric dependency cases and mortality, providing valuable insights into the leading causes of dependency, causes of mortality in children and adolescents, places of death, trends in mortality, and care locations.

Aligned with the study's first objective, which explores the legislative and policy framework governing pediatric palliative care, qualitative findings revealed that the regulation for granting the right to palliative care at end-of-life, which is accessible for individuals of all ages and

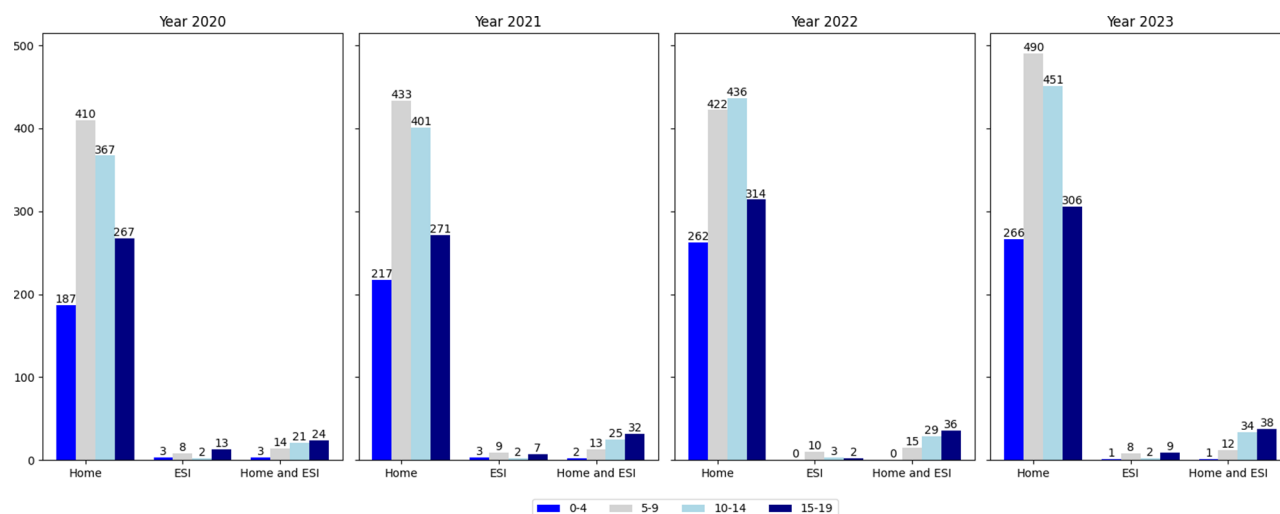


Fig. 6 Number of children under long-term care insurance by age group and place of care (2020–2023). Original data from: The government of the Grand Duchy of Luxembourg, Ministry of Health and Social Security. General Inspectorate of Social Security. (April 2024). Note: Intermittent Stay and Care Establishments (Établissement d’aides et de soins à séjour intermittent, ESI)

Table 4 Distribution of children under Long-Term care insurance by age and place of care (2020–2023)

Year	Age Group	Home	ESI	Home and ESI	Chi2	P-value
2020	0–4	187	3	3	27.001	0.0001
	5–9	410	8	14	df: 6	
	10–14	367	2	21		
	15–19	267	13	24		
2021	0–4	217	3	2	36.068	< 0.0001
	5–9	433	9	13	df: 6	
	10–14	401	2	25		
	15–19	271	7	32		
2022	0–4	262	0	0	47.161	< 0.0001
	5–9	422	10	15	df: 6	
	10–14	436	3	29		
	15–19	314	2	36		
2023	0–4	266	1	1	56.29	< 0.0001
	5–9	490	8	12	df: 6	
	10–14	451	2	34		
	15–19	306	9	38		

* The numbers are cumulative and include both new and ongoing cases from previous years

Original data from: The government of the Grand Duchy of Luxembourg, Ministry of Health and Social Security. General Inspectorate of Social Security. (April 2024).

Table 5 Distribution of children (0–19 Years) covered by Long-Term care insurance cared exclusively at home (2020–2023)

Year	Total Children Exclusively Cared for at Home	Linear Regression
2020	1231	R ² : 0.99
2021	1322	p: 0.0020
2022	1434	Slope: 95.8
2023	1513	

*The numbers are cumulative and include both new and ongoing cases from previous years

Original data from: The government of the Grand Duchy of Luxembourg, Ministry of Health and Social Security. General Inspectorate of Social Security. (April 2024)

typically limited to 35 days with exceptional extensions, may fail to adequately meet the needs of children with life-limiting or life-threatening conditions. These conditions often extend for years, spanning into young adulthood with evidence showing increased survival rates [10, 38–40]. International recommendations by the World Health Organization emphasize that PPC begins at the time of diagnosis and continues irrespective of whether the child is receiving curative treatment [2]. In our study, it was evident that the number of children granted the right to palliative care between 2020 and 2023 was limited, with right initiation only during the end-of-life period. This aligns with findings that highlight various

barriers including legislative and health professionals obstacles, to referrals for pediatric palliative care [41].

Aligned with the study's second objective, which explores the availability of pediatric palliative care services and resources in Luxembourg, this analysis focuses on the current care structure, highlighting both challenges and gaps. According to the Together for Short Lives guide, children requiring palliative care need services at one of three levels: universal, intermediate, or specialized, depending on their specific needs and conditions [6]. Our findings indicate that Luxembourg's current structure has not yet reached the universal level, which is the first level of service provision. Psychological support is provided through associations, alongside the limited availability of home care networks adopting a pediatric palliative care approach. While inpatient pediatric palliative care is available in hospitals, the absence of a specialized pediatric mobile team, insufficient training in pediatric palliative care, particularly for pediatric nurses given the specialized field, and the lack of respite homes for children indicate that intermediate or specialized levels of care have not yet been achieved, consistent with other findings [4, 5, 42, 43]. These findings have important implications for the development of pediatric palliative care in Luxembourg. The gaps observed call for a more structured and integrated national approach. In line with WHO recommendations [44], pediatric palliative care should be integrated across all levels of the healthcare system (from community to tertiary care) and delivered through appropriate models of care, whether at a universal, intermediate, or specialized level of service provision. These include home-based care supported by mobile teams, outpatient clinics, and dedicated inpatient services where needed, and respite care options to support families. Establishing clear policies, expanding training, and defining service standards across care settings would support the development of a more coordinated, child- and family-centered model of care. However, the introduction of pediatric palliative care courses for university nursing students specializing in pediatrics, as part of the objectives outlined in the national end-of-life and palliative care plan, represents a step toward addressing one critical gap, alongside the support provided by associations and the efforts of home care services.

In addition to these challenges, our findings highlight the lack of a respite home and the insufficiency of specialized facilities to accommodate children with life-threatening or life-limiting conditions or seem to lack other services for children that are not necessarily under the palliative care umbrella. The data revealed that the majority of children with dependency cases under long-term care insurance 93.5% in 2023 reside at home, with only a small proportion accessing Intermittent Stay and Care Establishments. Previous research has shown that

many parents, often the mother, leaves the workforce to provide full-time care, resulting in significant income loss [45], financial difficulties [45, 46], high expenses for medications [45] medical supplies [45] and special equipment [45]. Additionally, studies disclose that caring for children with serious illness can lead to psychological distress for the parents [46]. Similar research highlights the significant burdens on caregivers, in mothers of children with disabilities [47] or life-limiting conditions [48, 49] experiencing symptoms such as chronic stress, anxiety, depression, and physical health problems compared to parents of healthy children. Given these significant burdens on caregivers, respite homes have been recognized to provide temporary relief to family caregivers while improving well-being and reducing psycho-emotional distress [50, 51].

In line with the study's third objective, which examines pediatric dependency cases, secondary data from long-term care insurance highlighted a range of diagnoses for children up to 19 years old. Some of these diagnoses do not fall under pediatric palliative care categories, such as pervasive developmental disorders, mixed specific developmental disorders, attention-deficit hyperactivity disorders, mild intellectual disabilities, lack of expected normal physiological development in childhood, and speech and language developmental disorders [52, 53]. These conditions primarily require educational or rehabilitative support rather than palliative care [52, 53]. In 2023, 1,330 children were covered under Luxembourg's long-term care insurance, representing the most common cases rather than all conditions. Approximately 700 of these cases are linked to diagnoses that generally do not fall under pediatric palliative care categories. In contrast, diagnoses such as cerebral palsy, paraplegia and quadriplegia, and congenital malformations affecting multiple systems are classified under pediatric palliative care categories due to their progressive nature, irreversibility, or critical condition [3, 6, 9, 10, 54–56]. However, conditions such as epilepsy and Down syndrome may need individual assessment to determine whether they fall under pediatric palliative care categories, as eligibility depends not solely on the diagnosis but also on associated morbidities and the child's specific medical needs [3, 57, 58]. Despite that, the actual number of children requiring palliative care in Luxembourg remains uncertain. However, these secondary statistics estimate that annually, 500 to 600 children up to 19 years old in the country could fall under one of the pediatric palliative care categories.

The estimated 500 to 600 children requiring pediatric palliative care annually is based on available long-term care insurance data and mortality figures. Considering the absence of a national registry of diseases, this estimate may not fully capture all eligible cases. The long-term

care data used for these estimations represent the most common causes of dependency in children (0–19 years old) and only include children who are registered and receiving formal support. It is worth noting that the figured data does not comprehensively cover children under 2 years old with life-limiting or life-threatening conditions or those in pediatric palliative care categories who never enrolled in the long-term care insurance. Moreover, for some cases, palliative care eligibility depends not only on diagnosis but also on associated morbidities and the child's specific medical needs. Furthermore, this estimate does not account for children receiving specialized palliative care treatments outside Luxembourg, particularly those who have moved abroad and registered under another country's healthcare system. Additionally, mortality figures only account for children who passed away (decedents), while non-decedents or children living with serious conditions requiring palliative care may not be fully represented in long-term care insurance datasets.

Aligned with the study's third objective, which also examines causes of death in children and adolescents, this analysis highlights the main causes of mortality in Luxembourg and their implications for pediatric palliative care. These findings also emphasize the need for enhanced services and alignment with international guidelines, such as the WHO framework, to better support children with these conditions. In 2018, the WHO highlighted the medical and ethical need to make palliative care and pain relief available for all children in need, including those in high-income countries [44]. The WHO guide identified categories of conditions that require PPC, particularly at the end of life [44]. This guide is relevant when considering all causes of child mortality in Luxembourg. In our study, external causes of morbidity and mortality are reported as the highest (31.9%), among the pediatric population aged 0–19 years, usually resulting in sudden deaths or survival with long-term consequences that may endure into adulthood [59]. This corresponds to the global trends where injuries are the leading cause of death among children [60]. Perinatal conditions and congenital malformations with chromosomal abnormalities together are responsible for 30.7% and 10.8% of deaths, respectively, among the 0–19 age group in Luxembourg. These diseases could endure for days, weeks, and sometimes years before the death occurs and would need a pediatric palliative care approach and end-of-life care [55, 61]. To support retrospective identification of palliative care needs, death registries could include illness duration prior to death, especially for chronic or progressive conditions. Neoplasms are reported for 5.8% of child deaths among the 0–19 age group, these children fall under the first category of PPC, where curative treatments may fail [6, 9]. This finding aligns with global studies, which report that approximately 5.69% of individuals

aged 0–19 years with cancer require palliative care at the end of life [62]. Among children and teenagers aged 1–19 years in Luxembourg, neoplasms represent 11.4% of deaths, making them the second most common cause and highlighting the impact of pediatric cancers. Other studies have shown that comprehensive pediatric palliative care and end-of-life care are essential for efficiently managing symptoms and improving the quality of life for both children and their families [2, 6, 44, 62].

Strengths and limitations

This is the first scientific study in Luxembourg to estimate the number of children who may require a palliative care approach, based on national statistics from Luxembourg. By examining dependency cases from long-term care insurance data and linking disease diagnoses to pediatric palliative care categories. Additionally, death registry data were analyzed to highlight the need for palliative and end-of-life care across various causes of mortality.

To explore the current situation of pediatric palliative care in Luxembourg, this study employed a robust mixed-methods approach. Thematic analysis was applied to both a review of documents such as legislation, regulations, and national plans and data collected from participants representing multiple sectors and specialties, ensuring a comprehensive understanding of the findings. The input from participants provided a breadth of perspectives, enriching the study's insights. By combining qualitative and quantitative methods, this research offers a valuable model for addressing similar studies in other small countries or closely-knit healthcare systems. The findings highlight the available services and regulations, while also exposing critical gaps in the current system.

A significant limitation of this study is the lack of a national disease registry in Luxembourg, which limits the ability to accurately identify the pediatric population requiring palliative care, particularly children with life-limiting and life-threatening conditions. Establishing such a registry would improve tracking of needs over time and support more effective planning and allocation of resources. Another limitation of this study is the use of substitute values during data cleaning, where missing data were estimated based on predefined indicators or calculated using total sums for each row, as described in the methodology. While this approach prevented data loss and allowed for a more complete analysis, it introduces approximations that may have led to minor biases which should be considered when interpreting the results. Finally, the long-term care insurance data for 2023 were provisional when received in April 2024, as retroactive decisions for applications submitted before December 31, 2023, may still be processed.

Conclusion

This study sheds light on the current state of pediatric palliative care in Luxembourg, which stands at the universal services level, with primary initiatives from the healthcare system practiced. This study provides novel data on children who may fall under the pediatric palliative care umbrella, highlighting the urgent need to address existing gaps and develop a structured approach to meet increasing demands and unmet needs.

These findings highlight the importance of fully implementing the *National Plan for End-of-Life and Palliative Care (2023–2026)* as a foundational step toward improving pediatric palliative care in Luxembourg. In 2025, a pediatric palliative care course will be introduced for nursing students specializing in pediatrics at the University of Luxembourg, fulfilling a key National Plan objective. Additional efforts should include revising the legal framework to better meet the unique needs of children, developing education and training for pediatric healthcare professionals, and strengthening home-care services to ensure children receive quality palliative care in the comfort of their homes. Expanding medical coverage to include all necessary medications and supplies, refining eligibility criteria for long-term care insurance to include children under the age of two or those born with life-limiting or life-threatening conditions, strengthening psychosocial support for children and their families, promoting pediatric palliative care research, and creating a centralized national disease registry are all vital priorities.

Together, these measures will ensure that children with life-limiting and life-threatening conditions and their families receive support throughout their journey from diagnosis to end-of-life and bereavement. By building on advancements in adult palliative care, Luxembourg has the opportunity to create a specialized and comprehensive pediatric palliative care system that addresses the needs of children and their families.

Appendix

Appendix 1 Interview and Question Guide.

Note Not all questions were used with every participant. Questions were adapted based on the participant's role and expertise. Questions were asked either in open-ended interviews in -person or through videoconference, phone calls, or email.

- 1 What pediatric palliative care home services does your home-care network offer?
- 2 How do you support children with serious health conditions and their families throughout their care journey?

- 3 Can you describe the eligibility criteria for pediatric and neonatal patients to benefit from the long-term care insurance?
- 4 What palliative care topics are included within your curriculum, and how do they address pediatric needs?
- 5 What approaches and practices does your pediatrics department use to support children with serious illnesses, including those needing palliative care?
- 6 How is the social and financial support structured for children with life-limiting or life-threatening conditions?
- 7 In what ways do the existing laws and policies facilitate or hinder the provision of palliative care services for the pediatric population?

Abbreviations

PPC	Pediatric Palliative care
WHO	World Health Organization
LLC	Life-limiting conditions
LTC	Life-threatening conditions
GDP	Gross Domestic Product
SHI	Social Health Insurance
CNS	Caisse nationale de santé
COREQ	Consolidated Criteria for Reporting Qualitative Research
NGO	Non-Governmental Organization
CHL	Centre Hospitalier de Luxembourg
ICD-10	International Classification of Diseases, Tenth Revision
ESI	Établissement d'aides et de soins à séjour intermittent
ACT	Association for Children with Life-threatening or Terminal Conditions and their Families

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Author contributions

MM designed and developed the study, conducted data analysis and interpretation, and drafted the manuscript. JD and EA reviewed and revised the manuscript. MF co-designed the study methodology and revised the manuscript. All authors read and approved the final version of the manuscript.

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Data availability

The secondary data analyzed during the current study are not available for public use, due to confidentiality. However, summarized findings presented in this article are available within the publication.

Declarations

Ethics approval and consent to participate

The Ethics Review Panel of the University of Luxembourg approved the study (ERP 23–106 EOLC). All participants received oral and written study information. Informed consent was obtained from all participants, either in verbal or written form. The study did not involve experiments on humans or the use of human tissue samples.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

- World Health Organization. Palliative care [Internet]. 2020 [cited 2023 Dec 4]. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
- World Health Organization. Palliative care for children [Internet]. 2023 [cited 2023 Dec 4]. Available from: <https://www.who.int/europe/news-room/fact-sheets/item/palliative-care-for-children#:~:text=In%20the%20WHO%20European%20Region,high%2Dincome%20western%20European%20countries>
- Arias-Casais N, Garraida E, Rhee JY, Lima L, Pons JJ, Clark D, Hasselaar J, Ling J, Mosioiu D, Centeno C. EAPC Atlas of Palliative Care in Europe 2019 [Internet]. Vilvoorde: EAPC Press; 2019 [cited 2024 Mar 1]. Available from: <http://hdl.handle.net/10171/56787>
- Arias-Casais N, Garraida E, Pons JJ, Marston J, Chambers L, Downing J, et al. Mapping pediatric palliative care development in the WHO-European region: children living in low-to-middle-income countries are less likely to access it. *J Pain Symptom Manage*. 2020;1(4):746–53.
- Lizzie Chambers. A Guide to Children's Palliative Care (Fourth Edition) [Internet]. Together for Short Lives, England. 2018. Available from: <https://www.togetherforshortlives.org.uk/app/uploads/2018/03/TfSL-A-Guide-to-Children%E2%80%99s-Palliative-Care-Fourth-Edition-FINAL-SINGLE-PAGES.pdf>
- Vachon R. The State of Pediatric Palliative Care in Canada [Internet]. Cardus; 2024 [cited 2024 Apr 28]. Available from: <https://www.cardus.ca/research/health-reports/the-state-of-pediatric-palliative-care-in-canada/>
- Levine D, Lam CG, Cunningham MJ, Remke S, Chrastek J, Klick J, et al. Best practices for pediatric palliative cancer care: a primer for clinical providers. *J Support Oncol*. 2013;1(3):114–25.
- A guide for the development of children's palliative care services. Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health (RCPCH). Royal College of Paediatrics and Child Health. 2003 second edition.
- Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. Estimating the current and future prevalence of life-limiting conditions in children in England. *Palliat Med*. Oct; 2021;35(9):1641–51.
- Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA, et al. Rising National prevalence of life-limiting conditions in children in England. *Pediatrics*. 2012;1(4):e923–9.
- Klein C, Peltier F. La démographie luxembourgeoise en chiffres [Internet]. Luxembourg: Statec; 2023. Available from: <https://statistiques.public.lu/dam-assets/catalogue-publications/en-chiffres/2023/demographie-en-chiffres-2023.pdf>
- OECD, Luxembourg. Country health profile 2023. OECD Publishing; 2023.
- Creswell JW, Plano Clark VL. Designing and conducting mixed method research. 3rd ed. Thousand Oaks, CA: Sage; 2018.
- Polit DF, Beck CT. Nursing research: generating and assessing evidence for nursing practice. Eleventh edition. Philadelphia: Wolters Kluwer; 2021. p. 593.
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Heal*. 2007;care. 19(6):349–57.
- Polit DF, Beck CT. Nursing research: generating and assessing evidence for nursing practice. 11th ed. Philadelphia: Wolters Kluwer; 2021. pp. 498–9.
- Bowen GA. Document analysis as a qualitative research method. *Qual Res J*. 2009;9(2):27–40.
- Godin K, Stapleton J, Kirkpatrick SI, Hanning RM, Leatherdale ST. Applying systematic review search methods to the grey literature: a case study examining guidelines for school-based breakfast programs in Canada. *Syst Rev*. 2015;4:1–10.
- Le Gouvernement du Grand-Duché de Luxembourg, Administration d'évaluation et de contrôle de l'assurance dépendance. Définition [Internet]. 2024. Available from: <https://aec.gouvernement.lu/fr/l-assurance-dependance/definitions.html>
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;1(2):77–101.
- Labuschagne A. Qualitative research: Airy fairy or fundamental? [Internet]. 2003 p. 1. Available from: <http://www.nova.edu/ssss/QR/QR8>
- Guest G, Namey E, Chen M. A simple method to assess and report thematic saturation in qualitative research. Soundy A, editor. *PLOS ONE* [Internet]. 2020 May 5 [cited 2025 Jan 15];15(5):e0232076. Available from: <https://doi.org/10.1371/journal.pone.0232076>
- Polit DF, Beck CT. Nursing research: generating and assessing evidence for nursing practice. 11th ed. Philadelphia: Wolters Kluwer; 2021. p. 236.
- World Health Organization (WHO). Adolescent Health [Internet]. Available from: <https://www.who.int/health-topics/adolescent-health>
- Le Gouvernement du Grand-Duché de Luxembourg, Ministère de la Santé. Loi du 16 mars 2009 relative aux soins palliatifs, à la directive anticipée et à l'accompagnement en fin de vie [Internet]. 2009. Available from: <http://data.legilux.public.lu/eli/etat/leg/loi/2009/03/16/n1>
- Le Gouvernement du Grand-Duché de Luxembourg, Ministère de la Santé. Loi du 28 août 1998 sur les établissements hospitaliers [Internet]. 1998. Available from: <https://legilux.public.lu/eli/etat/leg/loi/1998/08/28/n1/jo>
- Le Gouvernement du Grand-Duché de Luxembourg, Ministère de la Santé. Règlement grand-ducal du 28 avril 2009 précisant les modalités d'attribution du droit aux soins palliatifs. [Internet]. 2009. Available from: <https://legilux.public.lu/eli/etat/leg/rgd/2009/04/28/n1/jo>
- Le Gouvernement du Grand-Duché de Luxembourg, Ministère de la Santé et de la Sécurité sociale. Règlement grand-ducal du 28 avril 2009 déterminant la forme et le contenu du carnet de soins de la personne soignée en fin de vie. [Internet]. 2009. Available from: <https://legilux.public.lu/eli/etat/leg/rgd/2009/04/28/n2/jo>
- Le Gouvernement du Grand-Duché de Luxembourg, Direction de la Santé, Ministère de la Famille, de l'Intégration et à la Grande Région. Plan national fin de vie et soins palliatifs [Internet]. 2023. Available from: <https://sante.public.lu/fr/publications/p/plan-national-fin-de-vie-2023.html>
- Le Gouvernement du Grand-Duché de Luxembourg, Ministère de la Santé. Plan National Cancer (PNC) 2014–2018 Rapport Final [Internet]. 2019. Available from: <https://sante.public.lu/dam-assets/fr/publications/r/rapport-final-plan-national-cancer-2014-2018/rapport-final-plan-national-cancer-2014-2018.pdf>
- Le Gouvernement du Grand-Duché de Luxembourg, Ministère de la Santé. Plan National Cancer Luxembourg 2014–2018. Concept de soins palliatifs pédiatriques. 2015.
- Le gouvernement du Grand Duché du Luxembourg [Internet]. 2023. Available from: <https://guichet.public.lu/fr/citoyens/travail/conges-jours-feries/situation-personnelle/conge-maladie-enfant.html>
- Le Gouvernement du Grand-Duché de Luxembourg, Ministère de la Sécurité sociale. Règlement grand-ducal du 13 décembre 2017 modifiant le règlement grand-ducal modifié du 18 décembre 1998 fixant les modalités de la détermination de la dépendance [Internet]. 2017. Available from: <https://legilux.public.lu/eli/etat/leg/rgd/2017/12/13/a1089/jo>
- de la Ministère. Famille, de l'Intégration et à la Grande Région, Ministère de la Santé, Ministère de la Sécurité Sociale. Guide des soins palliatifs [Internet]. 2009. Available from: <https://sante.public.lu/fr/publications/g/guide-soins-palliatifs-fr-de-pt.html>
- Le Gouvernement du Grand-Duché de Luxembourg, Administration d'évaluation et de contrôle de l'assurance dépendance. Prestations [Internet]. 2024. Available from: <https://aec.gouvernement.lu/fr/l-assurance-dependance/prestations.html>
- Le Gouvernement du Grand-Duché de Luxembourg, Le Ministre de la Santé, La Ministre de la Famille et de l'Intégration. Règlement grand-ducal du 8 février 2019 relatif à l'organisation de formations en soins palliatifs et en accompagnement de fin de vie pour les médecins, les autres professions de santé et le personnel d'encadrement des services pour personnes âgées [Internet]. 2019. Available from: <https://legilux.public.lu/eli/etat/leg/rgd/2019/02/08/a109/jo>
- Benini F, Papadatou D, Bernadé M, Craig F, De Zen L, Downing J et al. International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS. *J Pain Symptom Manage* [Internet]. 2022 May [cited 2024 Dec 15];63(5):e529–43. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S0885392421007119>

39. Broomfield J, Hill M, Guglieri M, Crowther M, Abrams K. Life Expectancy in Duchenne Muscular Dystrophy: Reproduced Individual Patient Data Meta-analysis. *Neurology* [Internet]. 2021 Dec 7 [cited 2024 Dec 15];97(23). Available from: <https://www.neurology.org/doi/https://doi.org/10.1212/WNL.00000000000012910>
40. Stephenson AL, Sykes J, Stanojevic S, Quon BS, Marshall BC, Petren K et al. Survival Comparison of Patients With Cystic Fibrosis in Canada and the United States: A Population-Based Cohort Study. *Ann Intern Med* [Internet]. 2017 Apr 18 [cited 2024 Dec 15];166(8):537. Available from: <http://annals.org/article.aspx?doi=10.7326/M16-0858>
41. Holder P, Coombes L, Chudleigh J, Harding R, Fraser LK. Barriers and facilitators influencing referral and access to palliative care for children and young people with life-limiting and life-threatening conditions: a scoping review of the evidence. *Palliat Med* [Internet]. 2024 Oct [cited 2024 Dec 15];38(9):981–99. Available from: <https://doi.org/10.1177/02692163241271010>
42. Arias-Casais N, Garralda E, Rhee J. EAPC atlas of palliative care in Europe. Romania [Internet]. 2019 [cited 2024 Mar 1];122(6). Available from: <http://hdl.handle.net/10171/56787>
43. Wager J, Kubek LA, Brenner M, Calmanti S, Doyle C, Lövgren M et al. Expert survey on coverage and characteristics of pediatric palliative care in Europe – a focus on home care. *BMC Palliat Care* [Internet]. 2022 Oct 17 [cited 2024 Apr 29];21(1):185. Available from: <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-022-01078-0>
44. World Health Organization. Integrating palliative care and symptom relief into paediatrics: a WHO guide for health-care planners, implementers and managers [Internet]. Geneva: World Health Organization. 2018 [cited 2024 Dec 17]. 87 p. Available from: <https://iris.who.int/handle/10665/274561>
45. Rallison LB, Raffin-Bouchal S. Living in the In-Between: Families Caring for a Child With a Progressive Neurodegenerative Illness. *Qual Health Res* [Internet]. 2013 Feb [cited 2024 Dec 16];23(2):194–206. Available from: <https://journals.sagepub.com/doi/10.1177/1049732312467232>
46. Boyden JY, Hill DL, Nye RT, Bona K, Johnston EE, Hinds P et al. Pediatric Palliative Care Parents' Distress, Financial Difficulty, and Child Symptoms. *J Pain Symptom Manage* [Internet]. 2022 Feb [cited 2024 Dec 16];63(2):271–82. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S0885392421004929>
47. Brekke I, Alecu A. The health of mothers caring for a child with a disability: a longitudinal study. *BMC Womens Health* [Internet]. 2023 Nov 30 [cited 2025 Jan 21];23(1):639. Available from: <https://bmcmwomenshealth.biomedcentral.com/articles/https://doi.org/10.1186/s12905-023-02798-y>
48. Fisher V, Atkin K, Fraser LK. The health of mothers of children with a life-limiting condition: A qualitative interview study. *Palliat Med* [Internet]. 2022 Oct [cited 2025 Jan 21];36(9):1418–25. Available from: <https://journals.sagepub.com/doi/https://doi.org/10.1177/02692163221122325>
49. Fraser LK, Murtagh FE, Aldridge J, Sheldon T, Gilbody S, Hewitt C. Health of mothers of children with a life-limiting condition: a comparative cohort study. *Arch Dis Child* [Internet]. 2021 Oct [cited 2025 Jan 21];106(10):987–93. Available from: <https://adc.bmj.com/lookup/doi/10.1136/archdischild-2020-320655>
50. Remedios C, Willenberg L, Zordan R, Murphy A, Hessel G, Philip J. A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions. *Palliat Med* [Internet]. 2015 Mar [cited 2025 Feb 11];29(3):223–30. Available from: <http://ps://doi.org/10.1177/0269216314560008>
51. Hizanu (Dumitrache) M, Boeriu E, Tanasescu S, Balan A, Oprisoni LA, Popa MV et al. Benefits of Respite Services on the Psycho-Emotional State of Families of Children Admitted to Hospice Palliative Care Unit: Preliminary Study on Parents' Perceptions. *Healthcare* [Internet]. 2024 Mar 29 [cited 2025 Feb 11];12(7):748. Available from: <https://www.mdpi.com/2227-9032/12/7/748>
52. Becker-Redding U, Neumann K, Schönweiler R. Special Kinds of Developmental Disorders of Speech and Language. In: Am Zehnhoff-Dinnesen A, Wiskirka-Woznica B, Neumann K, Nawka T, editors. *Phoniatrics I* [Internet]. Berlin, Heidelberg: Springer Berlin Heidelberg; 2020 [cited 2024 Dec 15]. pp. 607–17. (European Manual of Medicine). Available from: http://link.springer.com/https://doi.org/10.1007/978-3-662-46780-0_10
53. Waizbard-Bartov E, Fein D, Lord C, Amaral DG. Autism Severity and its Relationship to Disability. *Focus* [Internet]. 2024 Apr [cited 2024 Dec 15];22(2):252–62. Available from: <https://doi.org/10.1176/appi.focus.24022007>
54. Santos IBD, Sales JMR, Alencar VO, Nascimento IRCD, Andrade CAFGD, Neves CC et al. Clinical-epidemiological profile of children in palliative care. *Rev Bioét* [Internet]. 2023 [cited 2024 Dec 15];31:e3293PT. Available from: http://www.scielo.br/scielo.php?script=sci_arttext%26pid=S1983-80422023000100506%26tIng=en
55. Hoell JI, Weber H, Warfsmann J, Trocan L, Gagnon G, Danneberg M et al. Facing the large variety of life-limiting conditions in children. *Eur J Pediatr* [Internet]. 2019 Dec [cited 2024 Dec 15];178(12):1893–902. Available from: <http://link.springer.com/10.1007/s00431-019-03467-9>
56. Fraser L, Bedendo A, Jarvis S. Children with a Life-Limiting or Life-Threatening Condition in Wales: Trends in Prevalence and Complexity [Internet]. University of York; 2023 [cited 2024 Dec 15]. Available from: <https://eprints.whiterose.ac.uk/201985/>
57. Bull MJ, the Committee on Genetics. Health Supervision for Children With Down Syndrome. *Pediatrics* [Internet]. 2011 Aug 1 [cited 2024 Dec 15];128(2):393–406. Available from: <https://publications.aap.org/pediatrics/article/128/2/393/30609/Health-Supervision-for-Children-With-Down-Syndrome>
58. Minardi C, Minacapelli R, Valastro P, Vasile F, Pitino S, Pavone P et al. Epilepsy in Children: From Diagnosis to Treatment with Focus on Emergency. *J Clin Med* [Internet]. 2019 Jan 2 [cited 2024 Dec 15];8(1):39. Available from: <https://www.mdpi.com/2077-0383/8/1/39>
59. Peden M, World Health Organization. World report on child injury prevention. In Geneva: World Health Organization; 2008 [cited 2024 Dec 17]. p. 211. Available from: <https://iris.who.int/handle/10665/43851>
60. Li C, Jiao J, Hua G, Yundendorj G, Liu S, Yu H et al. Global burden of all cause-specific injuries among children and adolescents from 1990 to 2019: a prospective cohort study. *Int J Surg* [Internet]. 2024 Feb 12 [cited 2024 Dec 17]; Available from: <https://journals.lww.com/10.1097/JS9.0000000000001131>
61. Nageswaran S, Hurst A, Radulovic A. Unexpected Survivors: Children With Life-Limiting Conditions of Uncertain Prognosis. *Am J Hosp Palliat Med* [Internet]. 2018 Apr [cited 2024 Dec 17];35(4):690–6. Available from: <https://journals.sagepub.com/doi/10.1177/1049909117739852>
62. Connor S, Sepulveda Bermedo MC, editors. Global Atlas of Palliative Care at the End of Life [Internet]. 2014; Available from: https://waltherglobalpalliativecare.iu.edu/resources/international-resources/doc-files/worca_global_atlas_of_palliative_care_2014.pdf

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