



The state of Pediatric Palliative Care in Luxembourg: An Exploratory Mixed Methods Study

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What services are available for children with life-limiting or life-threatening conditions, and what is the status of pediatric palliative care in Luxembourg?



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- Over 21 million children globally require a palliative approach. Of this, more than 8 million need specialized palliative care services for children. (Connor et al, 2017)
- Around 170,000 children will die every year in Europe with health-related suffering and no access to palliative care. (Arias-Casais, Garralda, & Rhee, 2019)
- In Luxembourg, the National Cancer Plan from 2014-2018 estimates that 8-10 children with cancer need end-of-life care, while 40-50 children require palliative care yearly. (Direction de Santé, 2014)

Pediatric Palliative Care Services

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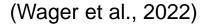
pediatric palliative care services national pediatric palliative care activities plan/ strategy PPHC CCS PPCU ICAH OCHS networks documents exist since exist exist exist nr exist exist nr (nr beds) exist nr (nr beds) exist nr Albania Armenia Austria 4(8) 1(4) 14 Ο 2012 Ο Ο Ο Belarus ۲ 3(25) Belgium 6 5 Bosnia and Hercegovina 11 Croatia 1 Czech Republic 3 3 Denmark 2014 5 5 2(4) 2 Estonia Finland 2019 5 5 22 France 2010 Germany 26 15 2(15) 17(200) 1 Greece Hungary 3 2 1(5) Iceland 1 Italy 2010 7 7 9(40) Lithuania 4(14) 1(6) Luxembourg Malta Netherlands 2013 8 8 14 2 North Macedonia Norway 2016 10 3 Poland 66 8(80) Portugal 1 5 1(30) 2010 2 1(8) Republic of Ireland Republic of Moldova 1 1(16) 2 Slovenia 2 22 30 Spain 2007 1(7) 1(8) 7 Sweden 1 1(8) Switzerland 2 3 Turkey 7 (100) 54 United Kingdom 11 11 9 18 19 21 20 5 16 11 exist= yes total nr (nr beds) 183 96 18(144) 117(434)

Table 2 Availability of national pediatric palliative care activities and pediatric palliative care services per country^a

Services of Pediatric Palliative Care in Europe

existent non-existent under development not stated

^a Exist Existence of, nr Number of, PPHC Pediatric palliative home care, CCS Clinical consultation services, PPCU Pediatric palliative care unit, ICAH Inpatient ch and adolescents' hospices, OCHS Outpatient children's hospice service









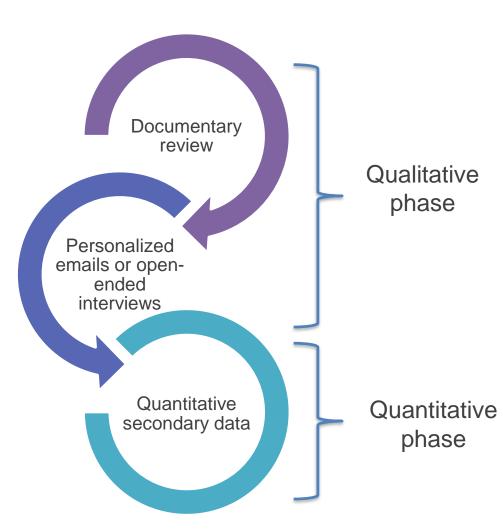


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Building Upon Existing Knowledge, Our State-of-play Sheds Light On Various Perspectives...

Methodology □ FACULTY OF SCIENCE, TECHNOLOGY AND MEDICINE

- January 2024 until May 2024
- Design: Exploratory Sequential mixed methods with a two-phase approach (Creswell & Clark, 2017)
- Sampling: Snowball and purposive
- Recruitment: Participants chosen for their experience, roles, and care for children with serious illnesses
- Analysis: Qualitative phase: Documentary analysis & Thematic analysis
 Quantitative phase: Description of secondary data

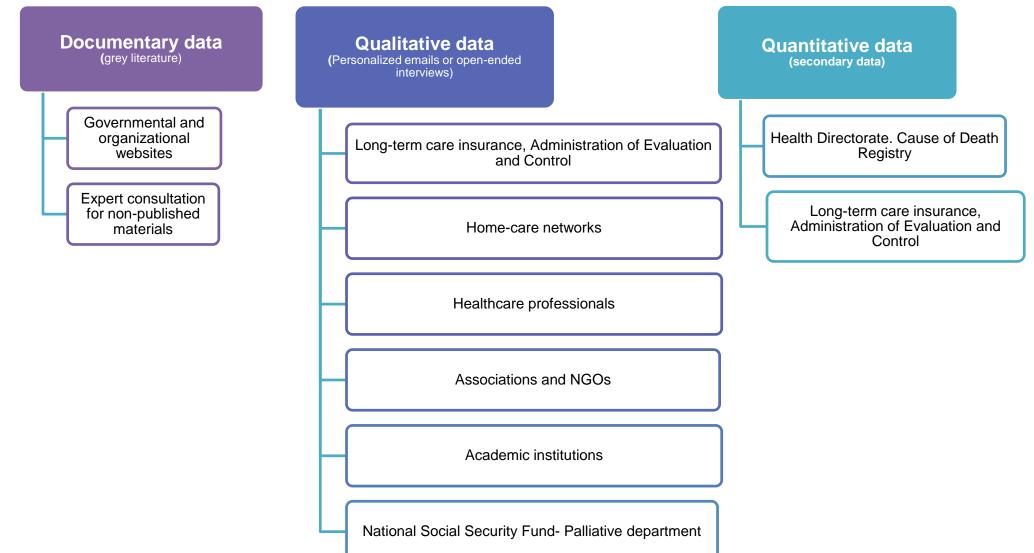


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Methodology: Data Collection

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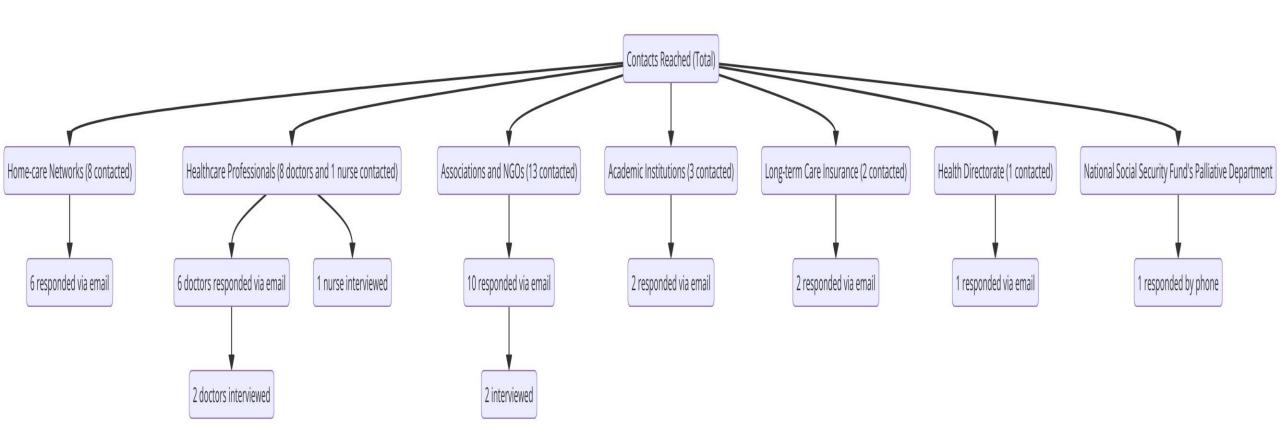




Methodology: Key Persons and Contact Response Overview

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- Total responses via personalized emails: 27
- Total interviewed: 5
- Phone call: 1

Results

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Qualitative data: Regulations and Services Overview

Progress of adult and pediatric palliative care in Luxembourg

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History timeline of palliative care in Luxembourg

Late 80s Volunteers of Red Cross & Caritas provides end-of-life care	1994 First palliative care unit at CHEM, pilot project with 5 beds	2005 Start of the PC project at HELP (homecare)	 2009 Law of March 16 on PC, advance directives, & EOL support Law on euthanasia, assisted suicide, and EOL Regulation of April 28, on procedures for granting the right to PC 	 regarding the rights and obligations of patients <i>"Plan National Cancer</i> 2014-2018 Mobile team & 10 beds unit at CHL hospital 	
Omega 90 founded Red Cross, Caritas, Amiperas, prompte the Ministry of Fam 1990	by and d by d by d by d by d by d by d by d b	arg's legislation the practice of ag profession of CHEM, He ospital nents certain cert	the continuity officially officially of ween the with 15 be of home	organi and er other l care Center) opens its doors ds • "Pour establi childre	

Progress pediatric palliative care in Luxembourg

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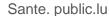
• The National Plan for End of Life and Palliative Care 2023-2026:

Axis 4: New care concept development specific to children

Organizing Pediatric Palliative Care	Providing Training In Pediatric Palliative Care	Addressing The Issue Of Euthanasia And Assisted Suicide In Minors	Establishment of a Respite Facility	
 Mobile expert team At diagnosis time, continues after age 18 up to age 27 	 PPC training into the nursing curriculum at UniLu (40 hours) General training on PPC 	 Prioritize PPC and psychological support for the family Adapt the legal framework 	Offer tailored palliative care services to children and families	Antoninery antonine series antonine series Mariana series Film De Vie ET Solins PALLI Film De Vie ET Solins PALLI



2023-2026



Specific leaves & support for parents

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Accompanying leave

- <u>5 working days per</u> case per year
- Terminally ill, firstdegree or seconddegree relatives

Leave for family reasons in the event of a child's illness

- Child under 18
- 0-4: 12 days off per child, 4-13: 18 days, 13-18: 5 days
- Maximum of 52 weeks

Supplementary allowance for children with a disability

• Cash assistance EUR 200

Night supervision

• Right for 10-day annual fee for night care

(Le gouvernement du Grand -Duché du Luxembourg, 2022) (Law of 16 March 2009 on palliative care, advance directives, and end-of-life care, 2009) (Le gouvernement du Grand -Duché du Luxembourg. 2023)

Home-care services for children with LLC or LTC

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services Home-care HC1 and HC2: do not provide PPC. One of them does not have a pediatric nurse

HC3: trained in general PC, modest demand on PPC, currently not accepting children with a palliative care booklet

HC4: PC for pediatrics is not common, having only one case since 2021

HC5: lately accepting pediatric patients, since July 2023 received one child, trained in general PC

HC6: offer PC, agreement with 2 hospitals, one of them is neonatal, last 5 to 6 years, few cases LLC were followed for 5 years & infants' months old followed shortly

Hospitalization & Key Associations for Children with LLC, LTC

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- Hospitalization:
- At the Centre Hospitalier de Luxembourg (CHL) KannerKlinik in the general pediatric ward or the intensive care unit.
- > Transferred to neighboring countries where enhanced expertise and resources are available

Key Associations

> Supporting children with serious illnesses and providing grief support for their families.

Results

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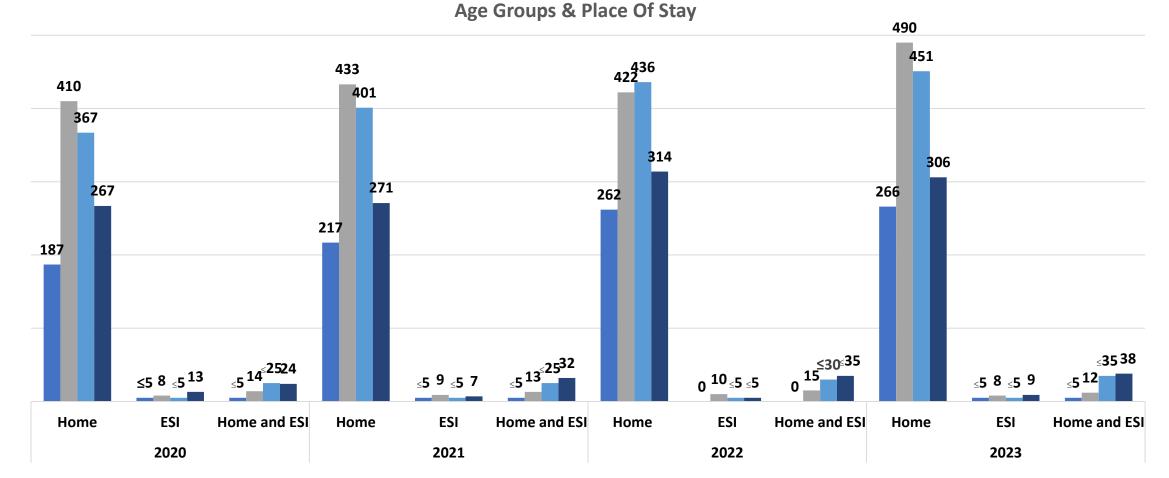
Quantitative Data: Long-term care insurance

Long-term Insurance Statistics

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Annual Evolution Of Children's Care Coverage By Long-term Care Insurance (2020-2023):



*Intermittent Stay and Care Establishments (ESI) * * All children are considered, regardless of their

affiliation or country of residence.

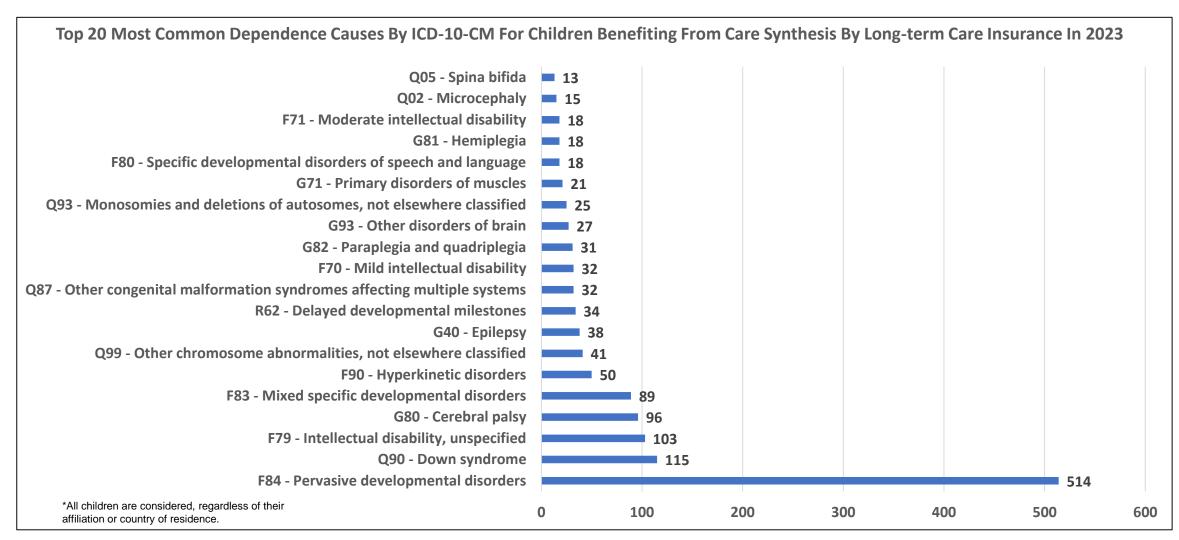
■ 0-4 ■ 5-9 ■ 10-14 ■ 15-19

The government of the Grand Duchy of Luxembourg, Ministry of Health and Social Security. General Inspectorate of Social Security. (2024).

Long-term Insurance Statistics

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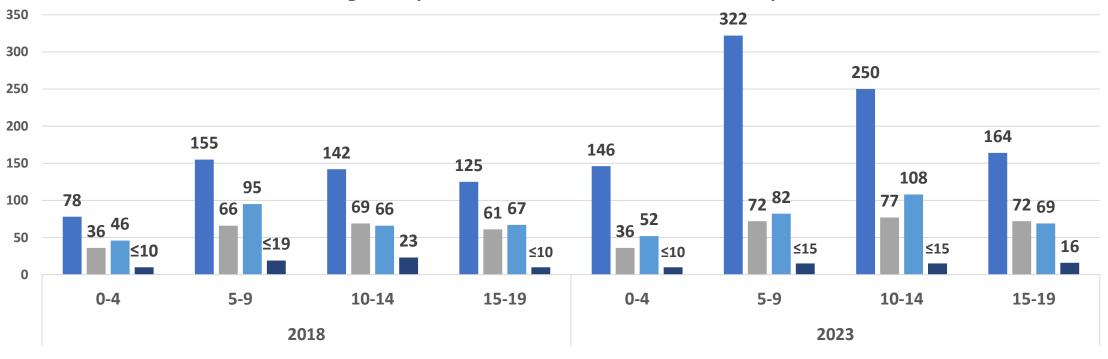
The government of the Grand Duchy of Luxembourg, Ministry of Health and Social Security. General Inspectorate of Social Security. (2024)

Long-term Insurance Statistics

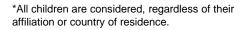
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Comparison of 2018 and 2023 for Children Receiving Care Synthesis by long-Term Care Insurance: Age Groups and Across Four Main ICD-10-CM Chapters



- Mental and behavioral disorders
- Diseases of the nervous system
- Congenital malformations and chromosomal abnormalities
- Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified



The government of the Grand Duchy of Luxembourg, Ministry of Health and Social Security. General Inspectorate of Social Security (2024).

Challenges And Recommendations

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Challenges And Recommendations

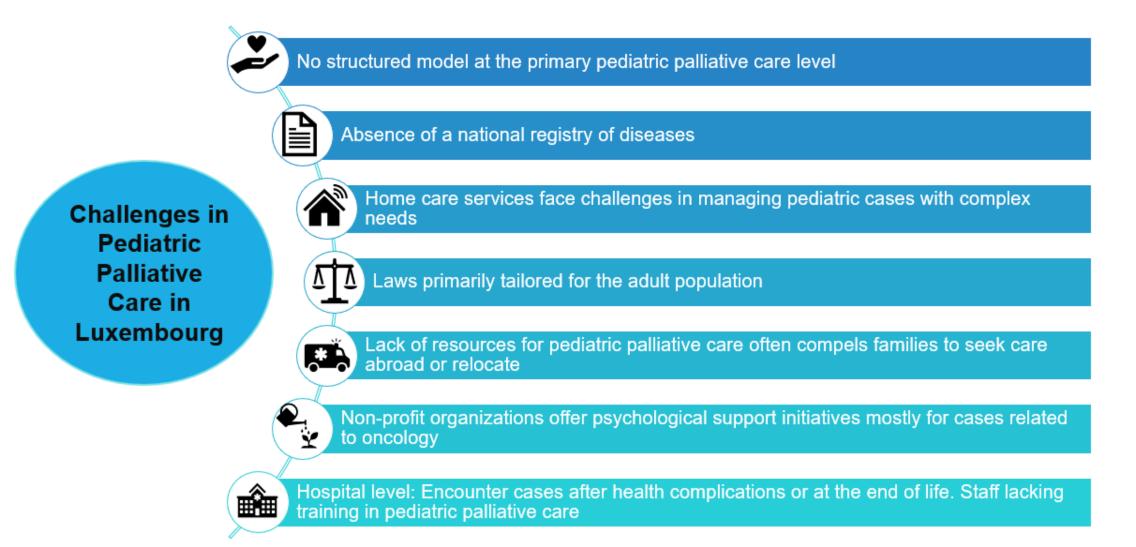
Limitation

The lack of a national registry in Luxembourg limits the ability to accurately estimate needs, track changes over time, and plan and allocate services effectively

Challenges And Recommendations

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Challenges And Recommendations

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Recommendation

- Implement the National Plan for End of Life and Palliative Care 2023-2026
- > Establishment of a mobile pediatric palliative care team within hospitals
- > Provide general and specialized training within academic institutions and continuous education
- Adjust regulations for the pediatric population in PC
- Create a respite care facility
- Raise community awareness
- Provide psychosocial support services
- Review and adjust the eligibility criteria for long-term care insurance
- Expand medical coverage
- > Establish and/or support associations dedicated to pediatric palliative care

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Thank you!

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