Research Square

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Acute Healthcare Utilization Among Children with Life-Limiting Conditions Throughout the Disease Trajectory: A Nationwide Population-Based Cohort Study

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Abstract

Background

Pediatric palliative care (PPC) aims to improve the quality of life of children with life-limiting or life-threatening conditions through early integration alongside disease-directed treatment. However, many eligible children remain under-recognized and underserved. We aimed to characterize acute healthcare utilization among children with life-limiting chronic conditions in Israel from diagnosis to death, with emphasis on the final year of life, and to compare utilization across age groups and geographic regions.

Methods

This retrospective population-based cohort study used electronic medical records from Clalit Health Services, Israel's largest health maintenance organization. Children aged 0–18 years diagnosed with life-limiting or life-threatening chronic conditions between 2000 and 2025 were included. Healthcare utilization throughout follow-up was analyzed.

Results

The cohort included 83,419 children (59.2% male; mean age at diagnosis 5.9 ± 5.9 years), of whom 3,267 (3.9%) died during follow-up. During the final year of life, 43.5% had ≥ 5 hospitalizations (mean 6.3 ± 7.7), 52.7% were admitted to the intensive care unit, and 16.0% had ≥ 5 emergency department visits. Community specialist consultations and imaging were frequent. In contrast, access to palliative care was minimal: 95.7% received no palliative consultation, while only 0.2% received hospice referral or pain consultation. Healthcare utilization differed significantly by age group and geographic region (both $p < 0.001$).

Conclusions

Children with life-limiting conditions experience intensive acute healthcare utilization, particularly near the end of life, despite extremely limited access to pediatric palliative care. These findings highlight a persistent gap and support expansion of pediatric palliative care services.

What is Known - What is New

What is Known: Children with life-limiting conditions have intense healthcare use near the end of life, and specialist pediatric palliative care is associated with less intensive acute care.

What is New: In a nationwide Israeli cohort of 83,419 children, acute care was high across the whole disease course, yet >95% of those who died received no palliative consultation, a gap persisting under

universal coverage.

Introduction

Over the last decade, pediatric palliative care has become a rapidly growing field. Expert reviews have refined the clinical categories of children who may benefit from such care: children with life-threatening conditions for which curative treatment may be possible but premature death remains likely; children with conditions for which there is no realistic hope of cure; children with progressive terminal disorders; and children with irreversible but non-progressive conditions requiring complex care.[1]

The World Health Organization defines pediatric palliative care as the active total care of the child's body, mind, and spirit, beginning at diagnosis and continuing regardless of whether the child is receiving disease-directed treatment.[2] The updated international standards developed through the Geography of Pediatric Palliative Care Study (GO-PPaCS project) similarly emphasize that pediatric palliative care should be available across settings and throughout the disease trajectory.[1] The American Academy of Pediatrics has likewise advocated for an integrated, multidisciplinary approach introduced from diagnosis.[3]

Recent population-based studies from the United Kingdom have documented a substantial and continuous increase in the prevalence of children living with life-limiting conditions. Fraser et al. demonstrated a rise from 26.7 per 10,000 in 2001/02 to 66.4 per 10,000 in 2017/18, with future increases predicted to continue.[4] This epidemiological shift has been accompanied by increasing healthcare complexity, further emphasizing the need for integrated palliative services throughout the disease course.[5,6]

Despite this growing need, access to pediatric palliative care remains uneven and frequently delayed. Studies have shown that a significant proportion of children with life-limiting conditions do not receive specialist palliative care, even in advanced stages of illness, particularly those with neurological, metabolic, and genetic conditions.[7] In the absence of timely palliative involvement, children are more likely to experience high-intensity healthcare utilization, including repeated hospitalizations, frequent emergency department visits, and increased reliance on intensive care.[8]

The system-level implications are substantial. A Canadian population-based study demonstrated mean healthcare costs in the last year of life of 78,332 Canadian dollars, with most expenditures attributed to acute care.[9] A cohort comparison demonstrated that children with access to specialist pediatric palliative care had fewer ICU days (RR 0.64), lower healthcare costs (RR 0.71), and a lower likelihood of dying in hospital (OR 0.67).[10] A systematic review of pediatric palliative care programs confirmed reductions in hospital admissions and costs.[11] More recently, evidence from Asian settings reinforces this picture: a Taiwanese nationwide population-based study found that specialized palliative care was received by only a fraction of eligible children,[12] and a Korean retrospective cohort study demonstrated

that introduction of specialized palliative care was associated with more advance care planning discussions and less mechanical ventilation near the end of life.[13]

In Israel, approximately 800 children died annually in 2019, over 60% under the age of one.[14] Despite Israel's universal national health insurance model,[15] which substantially reduces financial barriers, palliative care services remain largely underdeveloped and concentrated in oncology.[16] There is no comprehensive national data on the scope of the pediatric population requiring palliative care, nor on the acute healthcare services they use over time. This study was designed to address this gap, and aimed to estimate the scope of the pediatric population requiring palliative care and to characterize acute healthcare utilization among children from diagnosis until death or end of follow-up, with stratification by age group and geographic region.

Methods

This retrospective population-based cohort study utilized electronic medical records from Clalit Health Services, covering approximately 4.7 million members (~ 54% of the Israeli population). The study included children aged 0–18 years insured by Clalit and diagnosed with chronic life-limiting or life-threatening conditions.

The study was conducted in four sequential stages. First, children insured by Clalit who died between 1999 and 2025 were identified, and their chronic diagnoses extracted from hospital and community records. Through expert clinical review, 503 diagnoses were identified and grouped into 64 categories (Appendix 1). Second, this framework was applied to construct a cohort of children with a matching diagnostic profile diagnosed between 2000 and 2025. Third, detailed healthcare utilization data were extracted. Fourth, data were de-identified and transferred for analysis.

Extracted measures included: hospitalizations; ICU admissions; emergency department (ED) visits; community specialist consultations; imaging studies (X-ray, CT, MRI); rehabilitative services (physiotherapy, occupational therapy, speech therapy, child development services, nutritionist); and palliative care services (palliative consultation, hospice referral, pain consultation).

Descriptive analyses were performed. Continuous variables are presented as means and standard deviations (SDs) and categorical variables as frequencies. Comparisons across age groups (0–1, 1–5, 5–12, 12–18 years) and geographic regions (south, center, north) were performed using ANOVA and chi-square tests. A p-value < 0.05 was considered statistically significant. A planned logistic regression model for predictors of palliative service use was not performed due to extremely low event rates.

Results

The palliative care cohort included 83,419 children. The median follow-up time was 2,168.8 days (approximately 5.9 years) per patient, corresponding to a cumulative follow-up of 592,613 person-years across the study cohort. Of these, 59.2% were male, mean age at diagnosis 5.9 ± 5.9 years, and 3,267

(3.9%) died during follow-up (mean age at death 6.7 ± 5.8 years). The major diagnostic groups were metabolic diseases (38.4%), neuromuscular diseases (11.8%), cerebral palsy and other paralysis syndromes (9.9%), and malignancies of the lymphatic, hematologic, and related tissues (8.2%). Cohort characteristics are presented in Table 1.

Table 1
Cohort characteristics (N = 83,419)

Characteristic	**N**	**%**
Sex: Male	49,359	59.2%
Sex: Female	34,055	40.8%
Country of birth: Israel	80,946	97.0%
Country of birth: Outside Israel	2,473	3.0%
Socioeconomic status: High	11,603	15.1%
Socioeconomic status: Medium	43,426	56.3%
Socioeconomic status: Low	22,050	28.6%
Age at diagnosis: 0–1 years	26,992	32.4%
Age at diagnosis: 1–5 years	18,797	22.5%
Age at diagnosis: 5–12 years	18,166	21.8%
Age at diagnosis: 12–18 years	19,464	23.3%
Mean age at diagnosis ± SD (years)	5.9 ± 5.9	—
Median follow-up time (days)	2,168.8	—
Total cumulative follow-up (person-years)	592,613	—
Died during follow-up	3,267	3.9%
Mean age at death ± SD (years)	6.7 ± 5.8	—
District: South	11,814	15.6%
District: Center	30,045	39.7%
District: Jerusalem	9,983	13.2%
District: North	23,845	31.5%

SD, standard deviation.

Acute healthcare utilization during the last year of life (N = 3,267)

During the last year of life, 43.5% of children experienced ≥ 5 hospitalizations (mean 6.3 ± 7.7; median 4, IQR 1–9). From diagnosis until death, 55.6% had ≥ 5 hospitalizations (mean 12.5 ± 17.5). ICU admissions were common (any admission in 52.7% in the last year). ED use was frequent (16.0% with ≥ 5 visits in the last year). Community specialist consultations were extensive. By contrast, use of rehabilitative and psychological services was low. Use of palliative services was exceptionally limited: 95.7% received no palliative consultation in the last year, 0.2% received a hospice referral, and 0.2% received a pain consultation (Table 2).

Table 2
Key acute healthcare utilization during the last year of life (N = 3,267)

Measure	Last year, N (%)	Diagnosis to death, N (%)
Hospitalizations ≥ 5	1,422 (43.5%)	1,818 (55.6%)
Mean hospitalizations ± SD	6.3 ± 7.7	12.5 ± 17.5
Any ICU admission	1,722 (52.7%)	2,041 (62.5%)
Mean ICU admissions ± SD	1.0 ± 1.5	1.7 ± 3.0
ED visits ≥ 5	523 (16.0%)	1,031 (31.6%)
Mean ED visits ± SD	2.2 ± 3.1	5.0 ± 8.2
Community specialist consultations ≥ 5	1,605 (49.1%)	1,704 (52.2%)
X-ray studies ≥ 5	1,320 (40.4%)	1,630 (49.9%)
Physiotherapy (any)	210 (6.4%)	210 (6.4%)
Psychiatric consultation (any)	59 (1.8%)	126 (3.9%)
Palliative consultation: none	3,125 (95.7%)	3,112 (95.3%)
Hospice referral (any)	5 (0.2%)	9 (0.3%)
Pain consultation (any)	8 (0.2%)	14 (0.4%)

ICU, intensive care unit; ED, emergency department; SD, standard deviation. Last year of life: utilization during the 12 months preceding death.

Utilization by age group

Significant differences were found between age groups for most utilization indices ($p < 0.001$ in most cases; Fig. 1). Children aged 1–5 years and 5–12 years showed the highest rates of repeated hospitalization (≥ 5 hospitalizations in 47.4% and 48.2%, respectively, during the last year of life), emergency visits, and specialist consultations, whereas infants aged 0–1 year had higher rates of ICU admissions. Palliative service use was very low in all age groups.

Utilization by geographic region

In the south, higher hospitalization rates were documented during the last year of life (47.4% with ≥ 5 hospitalizations; mean 7.8 ± 9.9) compared with the center (41.8%; mean 5.7 ± 6.5) and north (41.5%; mean 5.6 ± 6.7; $p < 0.001$; Fig. 2). Emergency department visits were also more frequent in the south and center than in the north ($p < 0.001$). The north showed the highest rate of community specialist consultations (55.9% with ≥ 5), while imaging use was notably higher in the south for all modalities. Palliative service use, though universally low, was significantly higher in the south and center than in the north ($p < 0.001$).

Healthcare utilization among living children (N = 80,152)

Among living children (Fig. 3), during the last study year, 88.2% were not hospitalized and only 1.6% experienced ≥ 5 hospitalizations. Over the cumulative follow-up period, 14.3% experienced ≥ 5 hospitalizations (mean 2.8 ± 8.2). Community specialist consultations were very common cumulatively (83.9% with ≥ 5; median 28). Use of palliative services was strikingly limited: approximately 99.7% of living children received no palliative consultation during cumulative follow-up, hospice referral was given to only 3 children (0.004%), and pain consultation to 0.1%.

Stratification of healthcare utilization among living children by age group revealed a consistent and clinically meaningful gap between last-year and cumulative measures across all age groups (Fig. 4). The proportion of children with ≥ 5 admissions during the last study year was low across all age groups, ranging from 0.3% in the 5–12 year group to 1.1% in infants aged 0–1 year. In contrast, cumulative hospitalization burden was substantially higher, reaching 15.5% in infants and 18.8% in the 1–5 year group, reflecting the concentration of acute care events in early childhood. The pattern of community specialist consultations was similarly pronounced: while 40–51% of children in all age groups accumulated ≥ 5 specialist visits in the last study year alone, cumulative rates exceeded 90% in the youngest two age groups (94.4% in infants and 90.9% in children aged 1–5 years). In older children (5–12 years), cumulative rates were somewhat lower (61.4%), likely reflecting a shorter average follow-up duration rather than a lower underlying burden of care.

Discussion

In this nationwide population-based cohort study of more than 83,000 children with life-limiting conditions, we found a substantial and persistent burden of acute healthcare utilization throughout the disease trajectory, accompanied by remarkably limited use of specialist pediatric palliative care services. The care burden of life-limiting conditions in children accumulates substantially over time and is not adequately captured by cross-sectional assessments of a single year of follow-up. These findings are consistent with, and extend, the international literature.[5,6,8,17]

The pattern of utilization closely parallels findings from Canada, where Widger et al. found that most end-of-life healthcare costs derived from acute care.[9] The regional comparison by Lysecki et al., demonstrating that access to specialist palliative care was associated with fewer ICU days, lower costs, and lower hospital death rates,[10] suggests that the patterns observed in the current study might be substantially altered by systematic palliative care integration. A systematic review by Conte et al. corroborated these findings.[11] Taiwanese and Korean data confirm that similar challenges exist across different healthcare systems, but that implementation of structured palliative services can meaningfully alter patterns of care.[12,13]

The significant regional differences observed, higher hospitalization and imaging rates in the south, higher community specialist consultations in the north, likely reflect differences in service availability and referral patterns rather than underlying patient characteristics, given the universal healthcare context. Similar geographic variation in acute care use has been documented in other countries.[18]

The most striking finding remains the absence of palliative care involvement: over 95% of children who died received no palliative consultation. This contrasts sharply with international standards calling for early palliative integration from diagnosis.[1–3,5,6] This gap is clinically consequential: children with life-limiting conditions, both those with cancer and those with complex chronic conditions, experience a high burden of symptoms and suffering near the end of life,[19,20] which specialist palliative care is well positioned to address. In pediatric oncology, palliative involvement has been associated with meaningful differences in healthcare utilization and end-of-life outcomes,[21] yet in Israel such services have historically been concentrated in oncology and remain underdeveloped for non-malignant pediatric conditions.[16]

As with any study, several limitations should be considered. The analysis relies on administrative data, which cannot capture symptom burden or quality of life, and generalist palliative care may not be recorded as a distinct service. The observational design precludes causal inference, so the findings cannot determine whether earlier palliative integration would have altered healthcare utilization or clinical outcomes, and caution is warranted in generalizing to settings with different healthcare structures. A further limitation concerns temporal scope: the 25-year period (2000–2025) could not be stratified by calendar year, and patterns of palliative care provision in Israel have evolved considerably. The findings therefore reflect a historical aggregate rather than a snapshot of current practice and should not be interpreted as characterizing the present state of access; whether the pattern persists under more recent conditions cannot be determined from the available data. Several strengths should also be highlighted. This is a large population-based study drawing on prolonged data from both community and hospital settings, providing, for the first time, a broad national picture of children in Israel with chronic conditions that may lead to death. Its scale enhances the robustness of the findings and supports detailed subgroup analyses by age group, geographic region, and survival status. Critically, the study was conducted within a universal healthcare system in which minimal financial barriers make the persistent gap between high healthcare utilization and low palliative care use more likely to reflect

structural and organizational factors than ability to pay, a distinction particularly important when interpreting the observed underutilization. Finally, the ability to compare children who died with those who remained alive provides a perspective rarely available in the literature and highlights the relevance of pediatric palliative care beyond end-of-life care.

Conclusions

Children with life-limiting conditions in Israel consumed substantial acute healthcare resources throughout the study period, particularly near the end of life, and received very limited dedicated palliative care during this time. The evidence base from multiple countries demonstrates that early integration of pediatric palliative care can reduce acute care burden, lower healthcare costs, and improve quality of care.[9–13] These findings support reviewing and expanding palliative care provision for children with life-limiting conditions in Israel. Priority areas include systematic identification of children with palliative needs, expansion of hospital and community palliative services including home hospice, multidisciplinary team development, staff training, and integration of palliative care monitoring into national data systems. Such efforts should be informed by what families themselves describe as high-quality pediatric palliative care[22] and by honest, developmentally appropriate communication with children facing life-limiting illness.[23] Future prospective studies using current data are needed to assess whether patterns of palliative care access and acute healthcare utilization have changed in recent years.

Declarations

Acknowledgments

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Ethics approval: This study was conducted in accordance with the Declaration of Helsinki. Approved by the institutional review board (Helsinki committee) of Clalit Health Services: 0175-22-COM1. Given the retrospective design using de-identified administrative data, the requirement for individual informed consent was waived.

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Competing interests: The authors declare no competing interests.

Data availability: The data were obtained from Clalit Health Services and are not publicly available due to privacy and data-protection regulations governing Israeli health-fund records. De-identified data may be available from the corresponding author on reasonable request, subject to approval by the Clalit data authorities and the relevant Helsinki committee.

Author contributions: HL and TF contributed equally (conceptualization, methodology, investigation, drafting). TF and Y. Schonmann performed data curation and analysis. YDG, YL, and Y. Shvartzman contributed to investigation and interpretation. PSh conceived and supervised the study and acquired funding. RP supervised and administered the project. All authors reviewed and approved the manuscript.

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Figures

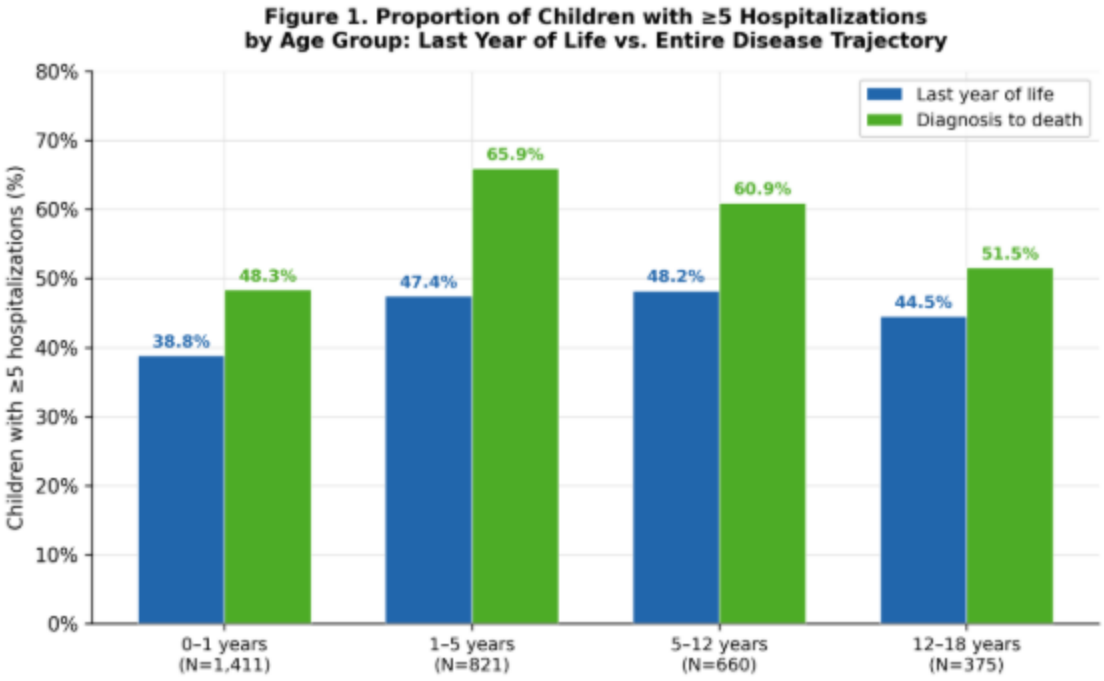


Figure 1

Proportion of children with ≥5 hospitalizations by age group: last year of life versus entire disease trajectory (children who died). p<0.001 for all comparisons across age groups.

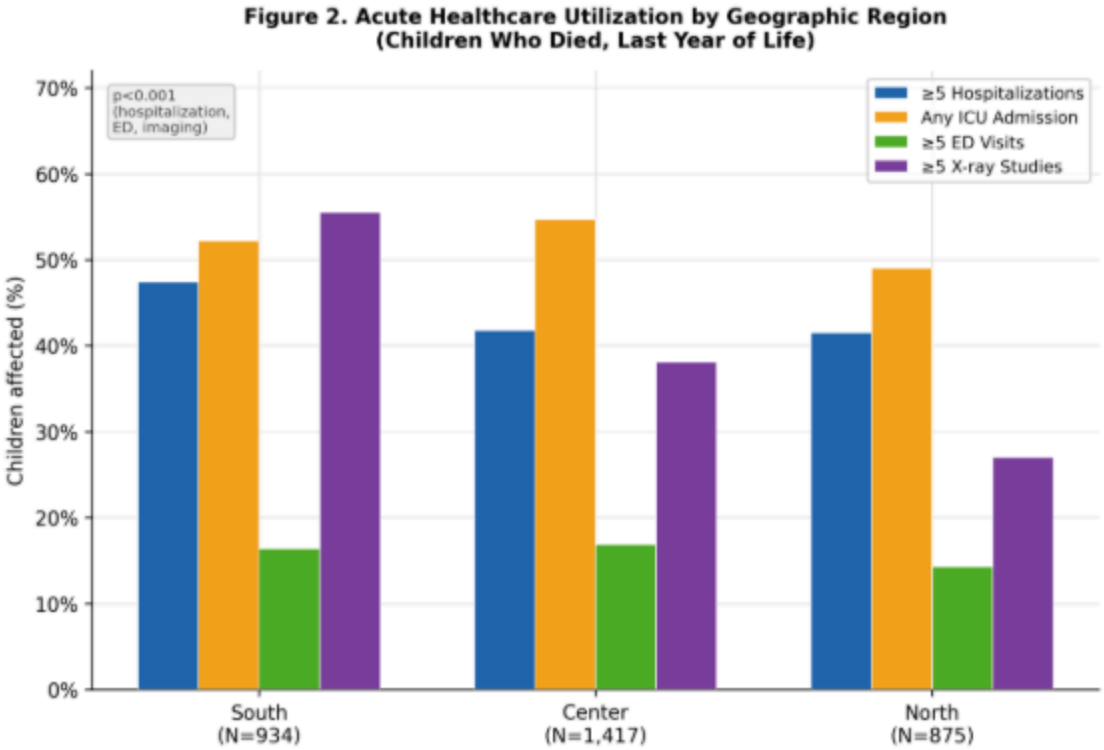


Figure 2

Acute healthcare utilization by geographic region among children who died (last year of life). The south showed significantly higher hospitalization rates and imaging use. p<0.001 for hospitalization, ED visits, and imaging comparisons.

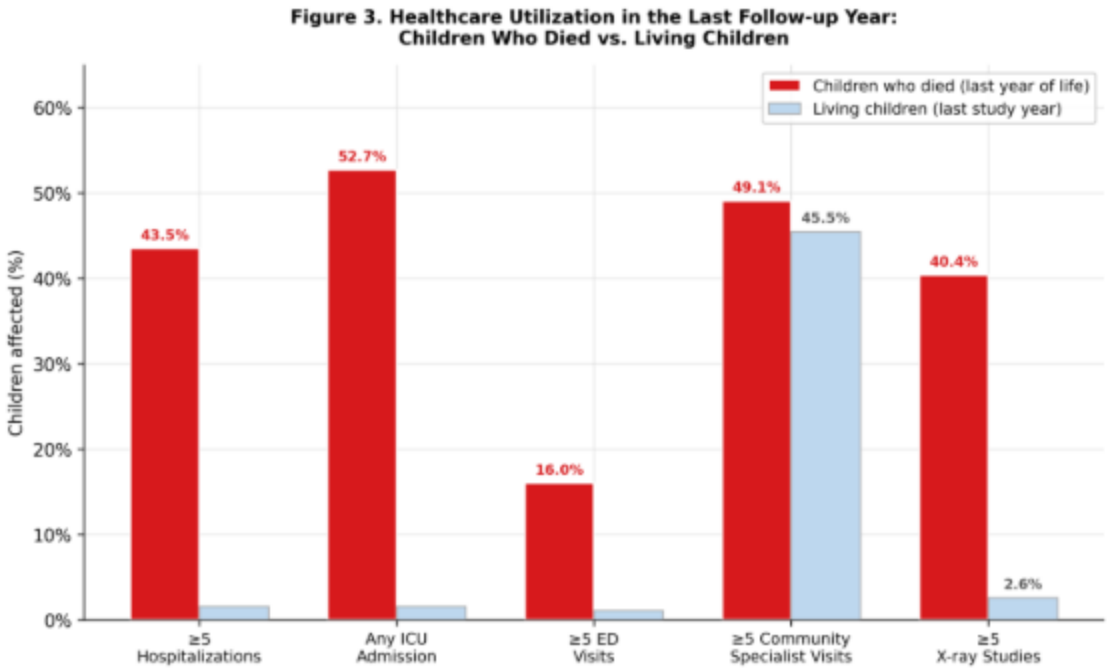


Figure 3

Healthcare utilization in the last follow-up year: children who died (N=3,267) versus living children (N=80,152).

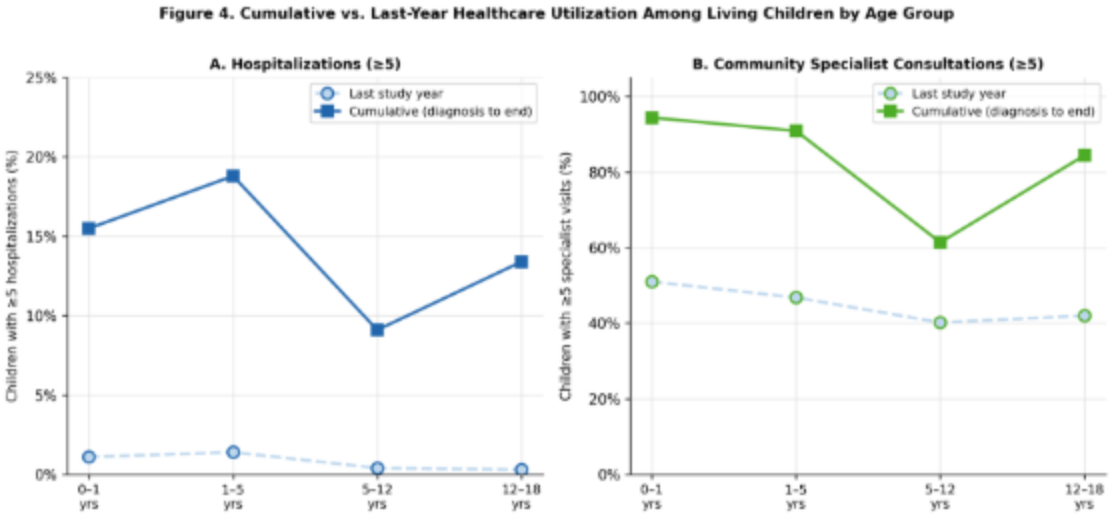


Figure 4

Cumulative versus last-year healthcare utilization among living children by age group: (A) proportion with ≥5 hospitalizations; (B) proportion with ≥5 community specialist consultations.