

## ORIGINAL ARTICLE

# Place of death among children from 0 to 17 years of age: A population-based study from Sweden

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## Abstract

**Aim:** The aim of this study is to contribute to the development of paediatric palliative care by investigating, on a population basis, where children in Sweden died, from 2013 to 2019. A particular focus was on comparing two groups: children who died during their first year of life with children who died at 1–17 years of age.

**Methods:** We hypothesised that there might be variations in place of death between the defined groups. Utilising national registry data, descriptive statistics were used to assess the distribution and variations in the place of death. Logistic regression analyses were conducted to ascertain the impact of associated factors.

**Results:** Most children died in hospitals (74.7%). The hypothesis postulating divergences in the place of death between age groups was not substantiated. Sex and birthplace showed no significant differences in home deaths. Deaths due to malignancies had a relatively high likelihood of occurring at home (39.0%). For perinatal diagnoses, the incidence of home deaths was relatively low (1.5%).

**Conclusion:** Children who received support from a specialist palliative service in their own homes were notably less likely to die in a hospital setting compared to those who did not receive such support. An unplanned hospital visit increased the likelihood of hospital death.

## KEYWORDS

end-of-life, home care, paediatrics, palliativemedicine

**Abbreviations:** CCC, Chronic complex conditions; CI, Confidence interval; Max, Maximum; Min, Minimum; N, Number; OR, Odds ratio; ROC, Receiver operating characteristic curve; SD, Standard deviation.

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## 1 | INTRODUCTION

Every child with a life-threatening or life-limiting illness has the right to receive palliative care. It is also very important to support their parents. The definition of paediatric palliative care includes the goal to improve the quality of life and wellbeing.<sup>1</sup> Paediatric palliative care is beneficial for conditions such as cancer, cystic fibrosis, muscular dystrophy, or irreversible non-progressive disabilities associated with a likelihood of premature death. There are regional variations in how palliative care is provided in Sweden. This is because the welfare system is influenced by decentralised healthcare structures, resulting in regional variations in the organisation, expertise, and resources of palliative care. In the Stockholm region, specialised paediatric palliative services are provided. Outside Stockholm, continuous specialised paediatric palliative services are absent. Instead, collaborative palliative teams—mostly dominated by care for adults—address the needs of individuals across age groups.<sup>2</sup>

Palliative care for children should be founded on the principles of child-centred care. Emphasising a child-centred perspective involves considering both the child's own wishes from the child's perspective and the adults' best solutions for the child, the so-called child perspective. Child-centred care involves a partnership between the child, the parents, and healthcare professionals. Each of these entities contributes to the child's care through their differing types of expertise. An ethical compass determining the child's best interests will guide the balance between the child's perspective and the adult-perceived child perspective in decision-making.<sup>3</sup> Several challenges exist in implementing child-centred care in paediatric palliative care. First, applying the definition of palliative care to paediatric settings can be challenging. The advancements in childhood cancer treatment have been successful, which has taken the focus off the introduction of palliative care. However, research has suggested that it is crucial to introduce both treatment options and a palliative approach,<sup>4</sup> and healthcare professionals' attitudes towards palliative care will impact its utilisation. Second, organisational barriers persist, including limitations in resources and opportunities to effectively manage health service systems.<sup>5</sup>

Decisions need to be taken in the best interests of a child when they do not have cognitive capacity to participate in a decision. This requires a partnership between healthcare professionals and family members.<sup>6</sup> During the palliative care process, parents often come to the realisation that they are the constant anchor in their child's care and become the individuals most familiar with their child's needs. Consequently, it is often the parents who are best placed to decide whether end-of-life care should be provided at home or in a hospital setting. Thus, it is essential to engage them in a collaborative partnership.<sup>7</sup> One study showed that when children were in need of palliative care, there was also a delicate balance in the ethical dilemma of determining to what extent healthcare professionals should engage in discussions about end-of-life decisions with parents, considering both the perspective of preserving life and that of allowing a peaceful letting go.<sup>7</sup>

### Key notes

- Understanding where children die is crucial for the organisation and distribution of tailored end-of-life care services.
- Most children died in hospitals and no difference was observed between the age groups.
- A national policy regarding paediatric palliative care structures is needed, in accordance with the needs of the child.

In addition to the family's preferences, the availability of resources also plays a significant role in planning for the child's care including decisions about place of care and the withdrawal of treatments. The evaluation of the place of death likely reflects a combination of the family's desires and the resources available in the region. It is important to assess and manage available resources for evaluating and treating symptoms. Such considerations are crucial for shaping the allocation of healthcare resources, especially in determining where children receive end-of-life care.

It has been demonstrated that adequate paediatric palliative care requires the ability to screen for symptoms such as pain, nausea<sup>8</sup> and a perception of quality of life.<sup>9</sup> Accordingly, the choice of place of death is dependent on healthcare resources and families' preferences. One study by Hakanson et al.<sup>10</sup> identified place of death as an important factor for the quality of end-of-life care for children. Another study suggested that inadequate provision of home support was as a reason for not choosing home as the place of death.<sup>11</sup> Reports by Nilsson et al.<sup>12</sup> stressed that the provision of paediatric palliative care should include both children and their families, and the quality should be equal, regardless of the place of care. In addition, the end-of-life experience can be influenced by the decision of place of death. It has been reported that the family's ability to plan their child's final place of care is associated with improved bereavement outcomes.<sup>13</sup> Furthermore, families' experience of palliative care has an influence on their own health for several years. In one study, parents whose children were affected by anxiety or disturbed sleep due to anxiety or pain reported an increased risk of long-term psychological morbidity.<sup>14</sup> In another study, Kreicbergs et al.<sup>15</sup> found that involving siblings in the decision-making processes regarding the preferred place of death was equally crucial, since the influence of palliative care also extends to them.

The access to different types of paediatric palliative care differs across Sweden due to regional variations. However, the development of paediatric home care has been ongoing in Sweden for several years.<sup>16,17</sup> The only national children's hospice is in Stockholm and it has five beds to cover the whole country.<sup>18</sup> A 2012 study evaluated place of death of children from 1 to 17 years of age with complex chronic conditions. In Sweden, 34.8% of the children died at home, and 62.3% of the children died in hospitals.

In addition, in Sweden, girls with complex chronic conditions had a lower frequency of dying at home compared to boys.<sup>10</sup> Research also highlighted that most parents prefer a home death,<sup>19</sup> and a qualitative study stressed that end-of-life palliative care at home enabled parents and other family members to feel a sense of control, presence and semblance of everyday life.<sup>20</sup> However, data regarding preferences for children and their families remain scarce, and more knowledge is needed. A study by Winger et al.<sup>21</sup> showed that such data was particularly valuable when it comes to children's individual preferences. Another study also identified the need to develop more advanced palliative care for children and their families.<sup>22</sup>

This study offers findings concerning the place of death for children in Sweden, an understanding of which is crucial for exploring the development of health care systems and for commenting on policy evaluation. This population-based study is part of a project on trends in the place of death encompassing all ages.

The aim of this study was to contribute to the development of paediatric palliative care and to investigate—at the population level—where children in Sweden died, from 2013 to 2019, with a particular focus on comparing those who died during their first year of life with children dying at 1–17 years of age.

We hypothesised that there might be variations in these locations between the two groups.

## 2 | METHOD

### 2.1 | Setting

The study years 2013–2019 were chosen for this cross-sectional population study. The reason was that the first national guidelines for palliative care for both children and adults were published in 2013.<sup>23</sup> The first national palliative care program for children was published in 2021,<sup>24</sup> and the results can serve as a baseline measurement for future evaluations of the national palliative care program for children. The decision to end in 2019 was also based on the assumption that the COVID-19 pandemic might have influenced the place of death in 2020–2022.

### 2.2 | Sample

The inclusion criterion was the availability of registered place of death for children aged under 1 year and 1–17 years of age. Data were obtained from national register holders. From the National board of welfare, we used the death certificate register to obtain underlying causes of death, the patient data register for information about hospital transfers and emergency department visits, and the national register for palliative care for information about utilisation of palliative care services. We obtained data about socioeconomic characteristics from registers at Statistics Sweden. Underlying causes of death were categorised based on diagnosis codes according to

International Classification of Diseases-10 for perinatal conditions, cancer, and neuromuscular conditions (Appendix S1).

### 2.3 | Analyses

Descriptive statistics were used to calculate the distribution and variations in place of death. To investigate variations in place of death and associated factors, binomial logistic regression modelling was performed with place of death as the dependent variable. Analyses were performed with hospital versus home as the dependent variable for all individuals residing in their own home. 'Other places' were excluded due to small numbers.

First, univariable analyses of each associated factor for place of death with univariable binary logistic regression analysis were performed. Calendar year was analysed both categorically and linearly. To determine the contribution of the associated factors, multivariable binary logistic regression analyses were performed for three prespecified groups of factors. Model one comprised gender and age. Model two added in cause of death, potential palliative care needs, and palliative care diagnosis. Model three encompassed gender, age, cause of death, palliative care needs, palliative care diagnosis, year of death, residing in urban areas, country of birth, and whether the individual received care in specialised palliative health care services. The model aimed to gain increased insight into the respective roles of these individual characteristics. Information about Swedish healthcare regions was added to study changes in the place of death within these regions, after adjusting for all significantly associated variables. The significance level for this study was set at  $p < 0.001$ . All analyses were performed using SAS version 9.4 (SAS Institute, Cary, North Carolina, USA).

## 3 | RESULTS

From 2013 to 2019, a total of 3002 children from 0 to 17 years of age died. Of these, 74.7% died in hospitals, 16.9% at home, 7.2% in other locations and 1.2% in nursing homes.

The data showed that 11.7% of children <1 year and 25.7% of children from 1 to 17 years of age died at home, other locations, 87.1% of children <1 year and 53.8% of children from 1 to 17 years of age died in hospitals, 0.4% of children <1 year and 2.4% of children from 1 to 17 years of age died in nursing homes, and 0.7% of children <1 year and 18% of children from 1 to 17 years of age died in other locations/unknown (Tables 1 and 2).

When stratified by sex, 17.3% of the boys and 16.5% of the girls died at home. The respective data for other locations were 73.3% of the boys and 76.5% of the girls died in hospitals, 1.0% of the boys and 1.3% of the girls died in nursing homes, and 8.4% of the boys and 5.7% of the girls died in other locations/unknown (Table 3).

Children supported by a specialist palliative service in their own home were significantly less likely to die in a hospital than those who

TABLE 1 Distribution of place of deaths from 2013 to 2019 by underlying cause of death and healthcare region in Sweden.

Cause of death	Healthcare region	Home death (%)	Hospital death (%)	Nursing home death (%)	Death in other places (%)
Perinatal diagnoses	Northern region	2 (3.4)	56 (96.6)	0 (0.0)	0 (0.0)
	Uppsala-Örebro region	2 (1.0)	203 (99.0)	0 (0.0)	0 (0.0)
	Stockholm region	3 (1.6)	186 (97.9)	1 (0.5)	0 (0.0)
	Western region	2 (1.2)	161 (98.8)	0 (0.0)	0 (0.0)
	South-eastern region	3 (2.7)	110 (97.3)	0 (0.0)	0 (0.0)
	Southern region	2 (1.0)	196 (98.0)	0 (0.0)	2 (1.0)
	Total	14 (1.5)	913 (98.2)	1 (0.1)	2 (0.2)
Malignancies	Northern region	8 (29.6)	19 (70.4)	0 (0.0)	0 (0.0)
	Uppsala-Örebro region	22 (43.1)	29 (56.9)	0 (0.0)	0 (0.0)
	Stockholm region	24 (32.9)	44 (60.3)	4 (5.5)	1 (1.4)
	Western region	18 (34.6)	34 (65.4)	0 (0.0)	0 (0.0)
	South-eastern region	19 (48.7)	20 (51.3)	0 (0.0)	0 (0.0)
	Southern region	21 (46.7)	24 (53.3)	0 (0.0)	0 (0.0)
	Total	112 (39.0)	170 (59.2)	4 (1.4)	1 (0.3)
Neuromuscular diseases	Northern region	8 (40.0)	10 (50.0)	1 (5.0)	1 (5.0)
	Uppsala-Örebro region	12 (24.5)	36 (73.5)	1 (2.0)	0 (0.0)
	Stockholm region	10 (13.7)	56 (76.7)	6 (8.2)	1 (1.4)
	Western region	7 (17.9)	31 (79.5)	0 (0.0)	1 (2.6)
	South-eastern region	6 (23.1)	20 (76.9)	0 (0.0)	0 (0.0)
	Southern region	15 (22.4)	52 (77.6)	0 (0.0)	0 (0.0)
	Total	58 (21.2)	205 (74.8)	8 (2.9)	3 (1.1)
Cardiovascular diseases	Northern region	3 (27.3)	8 (72.7)	0 (0.0)	0 (0.0)
	Uppsala-Örebro region	2 (5.0)	36 (90.0)	1 (2.5)	1 (2.5)
	Stockholm region	0 (0.0)	35 (100.0)	0 (0.0)	0 (0.0)
	Western region	5 (14.3)	30 (85.7)	0 (0.0)	0 (0.0)
	South-eastern region	4 (13.8)	24 (82.8)	0 (0.0)	1 (3.4)
	Southern region	0 (0.0)	29 (100.0)	0 (0.0)	0 (0.0)
	Total	14 (7.8)	162 (90.5)	1 (0.6)	2 (1.1)
Other CCC	Northern region	4 (10.5)	34 (89.5)	0 (0.0)	0 (0.0)
	Uppsala-Örebro region	11 (12.1)	80 (87.9)	0 (0.0)	0 (0.0)
	Stockholm region	10 (10.4)	83 (86.5)	2 (2.1)	1 (1.0)
	Western region	9 (12.0)	64 (85.3)	1 (1.3)	1 (1.3)
	South-eastern region	5 (13.2)	33 (86.8)	0 (0.0)	0 (0.0)
	Southern region	8 (13.6)	51 (86.4)	0 (0.0)	0 (0.0)
	Total	48 (12.1)	345 (86.7)	3 (0.8)	2 (0.5)
Other causes of death than CCC	Northern region	33 (34.7)	28 (29.5)	0 (0.0)	34 (35.8)
	Uppsala-Örebro region	72 (34.0)	93 (43.9)	3 (1.4)	44 (20.8)
	Stockholm region	40 (20.7)	109 (56.5)	5 (2.6)	39 (20.2)
	Western region	38 (22.0)	87 (50.3)	3 (1.7)	45 (26.0)
	South-eastern region	32 (33.7)	46 (48.4)	5 (5.3)	12 (12.6)
	Southern region	47 (28.5)	85 (51.5)	2 (1.2)	31 (18.8)
	Total	262 (28.1)	448 (48.0)	18 (1.9)	206 (22.1)
Total	Northern region	58 (23.3)	155 (62.2)	1 (0.4)	35 (14.1)
	Uppsala-Örebro region	121 (18.7)	477 (73.6)	5 (0.8)	45 (6.9)
	Stockholm region	87 (13.2)	513 (77.7)	18 (2.7)	42 (6.4)
	Western region	79 (14.7)	407 (75.8)	4 (0.7)	47 (8.8)
	South-eastern region	69 (20.3)	253 (74.4)	5 (1.5)	13 (3.8)
	Southern region	93 (16.5)	437 (77.3)	2 (0.4)	33 (5.8)
	Total	508 (16.9)	2243 (74.7)	35 (1.2)	216 (7.2)

Abbreviation: CCC, complex chronic conditions.

TABLE 2 Distribution of place of deaths from 2013 to 2019 by age and healthcare region in Sweden.

Age	Healthcare region	Home death (%)	Hospital death (%)	Nursing home death (%)	Death in other places (%)
<1 year	Northern region	27 (18.9)	113 (79.0)	0 (0.0)	3 (2.1)
	Uppsala-Örebro region	58 (13.8)	358 (85.4)	2 (0.5)	1 (0.2)
	Stockholm region	34 (8.3)	371 (90.0)	6 (1.5)	1 (0.2)
	Western region	35 (10.5)	295 (88.3)	0 (0.0)	4 (1.2)
	South-eastern region	27 (13.0)	180 (86.5)	0 (0.0)	1 (0.5)
	Southern region	38 (10.4)	322 (88.5)	0 (0.0)	4 (1.1)
	Total	220 (11.7)	1640 (87.1)	8 (0.4)	14 (0.7)
1–17 years	Northern region	31 (29.2)	42 (39.6)	1 (0.9)	32 (30.2)
	Uppsala-Örebro region	63 (27.5)	119 (52.0)	3 (1.3)	44 (19.2)
	Stockholm region	53 (21.4)	142 (57.3)	12 (4.8)	41 (16.5)
	Western region	44 (21.7)	112 (55.2)	4 (2.0)	43 (21.2)
	South-eastern region	42 (31.8)	73 (55.3)	5 (3.8)	12 (9.1)
	Southern region	55 (27.4)	115 (57.2)	2 (1.0)	29 (14.4)
	Total	288 (25.7)	603 (53.8)	27 (2.4)	202 (18.0)
Total	Northern region	58 (23.3)	155 (62.2)	1 (0.4)	35 (14.1)
	Uppsala-Örebro region	121 (18.7)	477 (73.6)	5 (0.8)	45 (6.9)
	Stockholm region	87 (13.2)	513 (77.7)	18 (2.7)	42 (6.4)
	Western region	79 (14.7)	407 (75.8)	4 (0.7)	47 (8.8)
	South-eastern region	69 (20.3)	253 (74.4)	5 (1.5)	13 (3.8)
	Southern region	93 (16.5)	437 (77.3)	2 (0.4)	33 (5.8)
	Total	508 (16.9)	2243 (74.7)	35 (1.2)	216 (7.2)

TABLE 3 Distribution of place of death in Sweden of children.

Variable	Total (n = 3002)	Hospital (n = 2243)	Nursing home (n = 35)	Home (n = 508)	Other place or unknown (n = 216)
Boys	1660 (100.0%)	1217 (73.3%)	17 (1.0%)	287 (17.3%)	139 (8.4%)
Girls	1342 (100.0%)	1026 (76.5%)	18 (1.3%)	221 (16.5%)	77 (5.7%)
0–1 year	1882 (100.0%)	1640 (87.1%)	8 (0.4%)	220 (11.7%)	14 (0.7%)
1–17 year	1120 (100.0%)	603 (53.8%)	27 (2.4%)	288 (25.7%)	202 (18.0%)
Age at death continuous	3.96 (5.95) 0 (0; 17) n = 3002	2.52 (4.83) 0 (0; 17) n = 2243	9.86 (6.79) 11 (0; 17) n = 35	6.11 (6.46) 3 (0; 17) n = 508	13.0 (5.0) 15 (0; 17) n = 216
Born in Sweden	2811 (100.0%)	2144 (76.3%)	28 (1.0%)	470 (16.7%)	169 (6.0%)
Born outside Sweden	191 (100.0%)	99 (51.8%)	7 (3.7%)	38 (19.9%)	47 (24.6%)
Number of emergency department visits					
None	2516 (100.0%)	1855 (73.7%)	26 (1.0%)	429 (17.1%)	206 (8.2%)
One unplanned health care visit	345 (100.0%)	282 (81.7%)	6 (1.7%)	49 (14.2%)	8 (2.3%)
Two or more unplanned health care visits	141 (100.0%)	106 (75.2%)	3 (2.1%)	30 (21.3%)	2 (1.4%)

Note: For categorical variables n (row %) is presented. For continuous variables Mean (SD)/Median (Min; Max)/n = is presented.

were not. A multivariable binomial regression analysis investigated living at home and dying in hospital versus dying at home, yielding an Odds Ratio (OR) of 0.07 (0.04–0.12) ( $p < 0.0001$ ) (Table 4).

Among the 508 children who died at home, 21.3% had two or more unplanned healthcare visits during the last month of life. Among the

(106) children who died in hospital, 75.2% had two or more unplanned healthcare visits. This figure was 2.1% for children dying in nursing homes, and 1.4% for children dying in other locations/unknown.

No significant difference was observed regarding the place of death when there were two or more unplanned healthcare visits.

TABLE 4 Multivariable binomial regression analyses for the likelihood of children dying in hospital vs dying at home of children in Sweden.

Variable	n	n missing	Value	n (%)	Multivariable <sup>a</sup>	
					OR (95% CI) Place of death	p-Value
Sex	1158	0	Boys	414 (66.5)	1.34 (1.02–1.76)	0.036
			Girls	384 (71.8)		
Underlying cause of death	1158	0	Perinatal diagnoses ref. <sup>c</sup>	41 (85.4)	1.00	<0.0001 <sup>b</sup>
			Malignant diseases vs. Perinatal diagnoses	150 (59.3)	0.52 (0.19–1.47)	0.22
			Neuromuscular diseases vs. Perinatal diagnoses	130 (72.6)	0.55 (0.22–1.39)	0.21
			Cardiovascular diseases vs. Perinatal diagnoses	64 (86.5)	0.99 (0.33–2.94)	0.99
			Other CCC <sup>d</sup> vs. Perinatal diagnoses	114 (83.8)	1.01 (0.38–2.67)	0.98
			Other causes of death than CCC <sup>d</sup> vs. Perinatal diagnoses	299 (63.9)	0.29 (0.12–0.69)	0.0051
Medical diagnoses with potential palliative care needs	1158	0	No	580 (72.0)	0.94 (0.58–1.53)	0.81
			Medical diagnoses with potential palliative care needs	218 (61.9)		
Place of death within a specialist palliative service	1158	0	No	767 (73.6)	0.07 (0.04–0.12)	<0.0001
			Yes	31 (26.7)		
Health Care Region	1158	0	Uppsala-Örebro region ref. <sup>c</sup>	164 (66.4)	1.00	<0.0001
			Northern region vs. Uppsala-Örebro region	59 (62.8)	0.84 (0.49–1.42)	0.51
			Stockholm region vs. Uppsala-Örebro region	196 (76.3)	2.88 (1.83–4.52)	<0.0001
			Western region vs. Uppsala-Örebro region	141 (69.8)	1.11 (0.73–1.70)	0.62
			South-eastern region vs. Uppsala-Örebro region	90 (63.4)	1.06 (0.66–1.70)	0.81
			Southern region vs. Uppsala-Örebro region	148 (68.5)	1.28 (0.84–1.96)	0.25

Note: p-Values, OR and Area under ROC-curve are based on original values and not on stratified groups. OR is the ratio for the odds for an increase of the predictor of one unit.

<sup>a</sup>Multivariable logistic regression model including Age at death continuous. Underlying cause of death, Potential palliative care needs, Place of death within a specialised palliative care facility and Health Care Region. Area under ROC-curve with 95% CI for multivariable model=0.72 (0.69–0.75).

<sup>b</sup>p-Value for the entire effect/factor/variable.

<sup>c</sup>The category is the reference variable.

<sup>d</sup>Complex chronic conditions.

Among the 508 children who died at home, 14.2% had one unplanned healthcare visit. Of the 2243 children who died in a hospital, 81.7% had one unplanned healthcare visit. This figure was 1.7% for nursing home deaths, and 2.3% for other locations/unknown (Table 3). A univariable binomial regression analysis investigated living at home and dying in hospital versus dying at home, yielding an OR of 3.84 (2.59–5.69) ( $p < 0.0001$ ) (Table 5).

There were no significant differences in the incidence of home deaths based on the child's country of birth. Among children born in Sweden ( $n = 2811$ ), 16.7% experienced home deaths. For those born outside Sweden ( $n = 191$ ), 19.9% died at home.

Examining regional distributions, the Northern region reported that 58 of the child deaths occurred at home—representing 23.3% of all child deaths in this region. For other regions, these figures were as follows: 69 (20.3%) for the South-eastern region, 121 (18.7%) for the Uppsala-Örebro region, 93 (16.5%) for the Southern region, 79 (14.7%) for the Western region, and 87 (13.2%) for the Stockholm region (Table 2). In the multivariable binomial regression analysis, there was a significant difference between Stockholm region vs Uppsala-Örebro region (Table 4). A multivariable binomial regression analysis investigated living at home and dying in hospital versus dying at home, yielding an OR of 2.88 (1.83–4.52) ( $p < 0.0001$ ).

TABLE 5 Univariable binomial regression analyses (living at home and dying in hospital vs. dying at home) for all associated variables of children in Sweden.

Variable	n	n missing	Value	n (%) of event	OR (95% CI) Place of death	p-Value	Area under ROC-curve (95% CI)
Age	1158	0	0–1 year	231 (72.2)			
			1–18 years	567 (67.7)	0.81 (0.61–1.07)	0.14	0.52 (0.49–0.55)
Country of birth	1158	0	Born in Sweden	722 (68.4)			
			Born outside Sweden	76 (73.8)	1.30 (0.82–2.05)	0.26	0.51 (0.49–0.53)
Medical diagnoses with potential palliative care needs	1158	0	No	580 (72.0)			
			Medical diagnoses with potential palliative care needs	218 (61.9)	0.63 (0.49–0.83)	0.0007	0.55 (0.52–0.58)
Number of emergency department visits	1158	0	None vs. None	506 (62.5)	1.00	<0.0001***	
			One unplanned health care visit vs. None	211 (86.5)	3.84 (2.59–5.69)	<0.0001	
			Two or more unplanned health care visits vs. None	81 (77.9)	2.12 (1.30–3.43)	0.0024	0.61 (0.58–0.63)

Note: All tests are performed with univariable logistic regression. *p*-Values, OR and Area under ROC-curve are based on original values and not on stratified groups. OR is the ratio for the odds for an increase of the predictor of one unit.

\*\*\**p*-Value for the entire effect/factor/variable.

In cases involving perinatal diagnoses, 14 of the deaths occurred at home, representing 1.5% of the deaths due to this diagnosis. This home death percentage was higher among children for other diagnoses—39.0% (112 children) for malignancies, 28.1% (262 children) for causes of death other than complex chronic conditions, 21.2% (58 children) for neuromuscular diseases, 12.1% (48 children) for complex chronic conditions, and 7.8% (14 children) for cardiovascular diseases (Table 1).

## 4 | DISCUSSION

The purpose of this study was to explore the specific places where children in Sweden died between 2013 and 2019. We hypothesised that there might be variations in these locations between children who died during their first year of life and children who died at 1–17 years of age. However, this study explored no statistically significant difference between these two groups.

There was a notably higher percentage of hospital deaths in our study than in an adult study carried out in Sweden during the same years. Specifically, among adults, 40.7% died in hospitals, 37.7% in nursing homes, 19.4% at home, and the remaining 2.2% in other places.<sup>25</sup> There are several potential explanations for this pattern, which warrant further investigation. One hypothesis could be that fewer children face mortality compared to adults, leading to a lack of well-established organisations with expertise in paediatric palliative care. Additionally, neonates with life-limiting diseases often die in neonatal intensive care units due to rapid deterioration following the cessation of intensive care. It is crucial to explore the potential for neonates to die at home. Another point to consider is that research indicated that parents were more likely to hold their child at the end of their life when the mother's residence was located far from the

hospital.<sup>26</sup> This suggested that families who lived farther from the hospital were more inclined to remain at their child's bedside or in nearby accommodation, often arranged by the hospital, thus allowing them to be closer to the infant during critical moments.<sup>26</sup>

Children who died in hospitals attended significantly more healthcare visits in the last month of life. We speculate that families might find resources for managing complications at home inadequate. This could have been because the hospital had an influence on the outcomes of the quality of life in conjunction with death. Further research is needed to confirm this and explore and improve the structures of organisations providing palliative care for children, aiming to ensure that healthcare professionals and parents can experience the satisfaction that home care may provide.

One objective in healthcare is to empower the child and their family to actively participate in decisions concerning the preferred location of the child's death. Attaining this goal requires seamless collaboration and flexibility among organisations. There is a need for specialised paediatric palliative care settings that concentrate on complex situations. There is also a need for preparedness and proficiency in addressing paediatric palliative care concerns across various healthcare domains for children with life-limiting illnesses. However, a study by Castor et al.<sup>2</sup> reported that, regrettably, healthcare professionals in this field often had inadequate training in end-of-life care, the management of complex symptoms, or the organisation of initiatives to promote advance care planning. Another study reported that healthcare professionals often associated paediatric palliative care primarily with end-of-life care, despite it being imperative for them to comprehend the comprehensive nature of the paediatric palliative concept.<sup>27</sup> All healthcare for children diagnosed with a life-limiting condition needs to incorporate the palliative concept right from the time of diagnosis.<sup>4</sup>

Sweden is a large country with a sparse population and it can be challenging to deliver comprehensive paediatric palliative care that adheres to the required standards. The growing prevalence of eHealth has emerged as a promising solution, facilitating the provision of advanced care over considerable distances. Although eHealth has not yet been adopted widely, numerous studies have emphasised its advantages.<sup>28</sup> To adequately provide appropriate palliative care for all children, regardless of their place of residence, the establishment of a national consulting team for paediatric palliative care could prove valuable in extending support for home healthcare across the nation. A possible alternative could be the formation of a consulting team for each of the six overarching healthcare regions.

Despite the challenges of implementing early paediatric palliative care, it is crucial to explore ways to integrate it seamlessly from the outset of a life-limiting diagnosis. This approach creates opportunities for both the child and the entire family to participate in decisions regarding the choice of the place of death. Early planning can enhance the likelihood of securing the appropriate resources at the right time for the child. Research suggested that the lack of opportunities for children to participate in the planning of their place of death is a significant challenge in paediatric palliative care.<sup>29</sup> To achieve the objective of child-centred care, the healthcare system needs to provide opportunities for both children and parents to participate in decisions regarding the place of death. In this context, it is essential to include all caregivers, encompassing both mothers and fathers, and actively listening to their individual perspectives.<sup>30</sup>

Although this study focused on Sweden, its findings are likely to be applicable to countries sharing similar healthcare policies and socioeconomic contexts. Related to this, an international study revealed substantial cross-national differences in the place of death among children with complex chronic conditions, influenced by socio-economic factors, healthcare policies, and cultural attitudes towards child fatalities.<sup>10</sup>

A key strength of the study was the utilisation of national registry data. This study also had some limitations. A registry study presupposes that diagnostic codes are accurately implemented. Otherwise, the results may be misleading and this can, therefore, be a source of error. Moreover, a registry study is unable to clarify the factors influencing the decisions regarding whether the child should die at home, in a hospital, or elsewhere. Consequently, assumptions can only be made based on other research that may provide potential explanations. These explanations need to be validated in further studies using both quantitative and qualitative approaches.

## 5 | CONCLUSION

The hypothesis regarding divergences in the place of death between children <1 year and children from 1 to 17 years of age was not substantiated. Children receiving support from a specialist palliative service in their own homes were notably less likely to die in hospital compared to those without such support. By contrast, an unplanned hospital visit increased the likelihood of hospital death.

## AUTHOR CONTRIBUTIONS

**Stefan Nilsson:** Conceptualization; writing – original draft; methodology; data curation. **Joakim Öhlén:** Conceptualization; writing – review and editing; methodology; data curation. **Stina Nyblom:** Writing – review and editing. **Anneli Ozanne:** Writing – review and editing. **Margaretha Stenmarker:** Writing – review and editing. **Cecilia Larsdotter:** Conceptualization; writing – review and editing; project administration; funding acquisition; methodology; data curation.

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## CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

## DATA AVAILABILITY STATEMENT

The data for this study is available from each register holder. Certain restrictions may apply. Programming codes are available from the authors upon reasonable request.

## ETHICS STATEMENT

The Swedish Ethical Review Authority stated that the study could be conducted without ethical review, since the sample consisted of deceased individuals (number 2019-05213, 2020-01758).

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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