**Inequality in place-of-death among children:**

**A Danish nationwide study**

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**Abstract**

***Objective:* To identify predictors for home death among children using socio-demographic factors and cause of death.**

***Design:* Nationwide registry study.**

***Patients:* A cohort of children (1-17 years) who died between 1 January 2006 and 31 December 2016.**

***Setting:* Denmark, Europe.**

***Main outcome measures:* Predictors for home death were assessed: Age, gender, diagnosis, region of residence, urbanicity, household income and immigrant status.**

***Results:* Of 938 deceased children included, causes of death were solid tumours (17.3%), haematological cancers (8.5%) and non-cancerous conditions (74.2%). A total of 25% died at home.**

**Compared to the lowest quartile, the groups with higher household income did not have a higher probability of dying at home (adjusted odds ratio (adj-OR): 0.8 (95% CI: 0.5-1.2/1.3)).**

**Dying of haematological cancers (adj-OR): 0.3 (95% CI: 0.2-0.7)) and non-cancerous conditions (adj-OR: 0.5 (95% CI: 0.3-0.7)) was associated with lower odds for home death compared to dying of solid tumors. However, being an immigrant was negatively associated with home death (adj-OR: 0.6 (95% CI: 0.4-0.9)).** **Moreover, a tendency was also found that being older, male, living outside the capital and in more urban areas were notable in relation to home death, however, not statistically significant.**

***Conclusions:* The fact that household income was not associated with dying at home may be explained by the Danish tax-financed health care system. However, having haematological cancers, non-cancerous conditions or being an immigrant were associated with lower odds for home death. Cultural differences along with heterogeneous trajectories may partly explain these differences, which should be considered prospectively.**

**Key words**

**Child; youth; pediatrics; end-of-life; place-of-death; Denmark**

**List of Abbreviations in alphabetical order**

**CI: Confidence Interval**

**DRCD: Danish National Register of Causes of Death**

**GP: General Practitioner**

**HI-EOL: High intensity treatment at end-of-life**

**MICE: Multiple Imputations with Chained Equations**

**OR: Odds Ratio**

**Introduction**

Internationally, there is an increasing focus on optimising end-of-life care for terminally ill children.1,2 High quality end-of-life care provided in the setting the family feels comfortable in is an important goal in paediatric palliative care.1 Another goal is to satisfy preferences for incurably ill children and their families regardless of diagnosis.3 Most terminally ill children and their families prefer to spend time and die at home4,5, but the majority of children die in hospitals.6-9

It is important to understand the broad range of factors influencing place-of-death for children. To identify disparities between children who die in hospital and at home, we recently performed a systematic review with a meta-analysis on factors associated with place-of-death among children.9 We found that **older age**, a **solid tumour cancer,** **white ethnicity** and **high socio-economic status** were associated with home death.6,10-22 However, since health care systems with inequality in access to health care may account for some of the disparities, knowledge is needed on whether inequality in home death plays a role in a tax-financed, equal-access health care system using complete and valid health care registry data.

The aim of this study was to identify predictors of home death among terminally ill children in Denmark focusing on socio-demographic factors and underlying cause of death.

**Methods**

We conducted a nationwide registry study in a cohort of deceased children.

Setting

Denmark has 5.8 million inhabitants and a free-access, tax-financed health care system.23 The unique Danish personal identification number (CPR number) issued to all Danish citizens makes it possible to merge data from national registries.

Denmark is divided into five administrative regions responsible for treatment provided by hospitals and general practitioners.24 The regions differ in relation to geography and populations.25 However, substantial homogeneity with regard to sociodemographic and health- related characteristics has been found between the five regions.25

In 2014, the Danish government decided to establish a palliative care program for children and adolescents with life-limiting diseases. The first children’s hospice opened in Copenhagen in 2015 and a second children's hospice opened five years later in 2020. In 2016, hospital-based specialised paediatric palliative care teams were established in each region providing hospital and in-home care.

Population

We included data on children between one and 17 years of age who died between 1 January 2006 and 31 December 2016.

Children below one year were excluded due to major dissimilarities in illness trajectories. Cases where death was caused by accidents, violence or suicides were also excluded.

Data from multiple national population registries were linked using the CPR number.

The population was identified through death certificate data retrieved from the Danish National Register of Causes of Death (DRCD), a registry comprising information on causes of death along with the date and place-of-death, reported by the doctor certifying the death.26

Place-of-death

Place-of-death was determined from the DRCD and divided into hospital death and home death. The Danish authorities have chosen to categorise hospice deaths as hospital deaths; unfortunately, we did not have the opportunity to investigate this further in the data.27

Information on place-of-death was missing in 40 cases (4.3%). According to Statistics Denmark, the lack of information was due to the introduction of electronic death certificates in 2007, which resulted in several missing death certificates.26 In the missing 40 cases, we determined place-of-death based on hospital admission status on the date of death in the DRCD, assuming that when the hospital admission included date of death, the child died at hospital.

Potential predictors

The choice of variables was based on the current evidence of potential predictors of home death7:

Age at death (1-4,5-9,10-13,14-17 years), gender, diagnosis (underlying cause of death in the DRCD and further grouped into: non-haematological cancer, haematological cancer and non-cancerous conditions), region of residence, urban versus rural municipality (provided by the Danish Centre for Food and Agriculture28), household income quartiles (latest reported income at least one year before the death of the child) and immigrant status (non-immigrant/immigrant including first and second generation descendants).

Statistical analysis

Descriptive statistics were calculated as prevalence proportions. Multiple logistic regression models were used to examine associations between potential independent variables and of home death. Associations were presented as mutually adjusted prevalence odds ratios (OR) and 95% confidence intervals (CI). All variables listed under potential predictors were included in multivariable analyses.

To account for missing values, we performed Multiple Imputations with Chained Equations (MICE) assuming that data were missing at random.29 A total of 53 MICE were made (25 on household income and seven on region of residence, urbanicity, household income and immigrant status, respectively). We fitted a multinominal logistic regression model generating 20 imputed datasets. Imputations were based on all variables used subsequently in the multivariate analyses.30 All comparative analyses were performed on the imputed datasets.

The statistical analyses were performed using STATA software.

Approval

The study was reported to the Danish Data Protection Agency through Aarhus University (record no. 2016-051-000001/977) and all data were stored and managed at secure servers at Statistics Denmark. According to Danish law, registry-based studies do not require ethics approval.

**Results**

*Study population characteristics*

A total of 3,814 children died in the study period. Of these, 2,414 died within their first year of life and 462 died of unnatural causes and were excluded. Hence, the final study population comprised 938 children.

Demographic characteristics are listed in Table 1. More than half of the children were boys (55%) and 40% died between one and four years of age. The median age at death was 8.5 years and causes of death were solid tumours (17%), haematological cancers (9%) and non-cancerous conditions (74%).

*Predictors for place-of-death*

In total, 25% of the children died at home. Predictors for home death are shown in Table 2.

With the age group 1-4 years of age as reference, the 5-9 year-old and the 14-17 year-old children both had a 1.3 higher probability of home death. Girls had a lower probability of dying at home than boys (adjusted OR: 0.7 (95% CI: 0.5-1.0).

Dying from haematological cancers (adjusted OR: 0.3 (95% CI: 0.2-0.7)) and non-cancerous conditions (adjusted OR: 0.5 (95% CI: 0.3-0.7)) was negatively associated with home death compared to dying from a solid tumour.

Differences were also seen according to region of residence of the child; a 1.5 higher probability for home death was seen in all regions but North Denmark Region compared with the Capital Region of Denmark. However, if the child lived in an area with a higher urbanicity-score, the probability for home death adjusted for which region of residence was 1.5-1.8 times higher than the children living in rural areas.

Using the group with the lowestquartile of household income as reference, we found that the three groups with higher quartiles of household income appeared to have a lower probability of dying at home when adjusting for the above-mentioned variables (OR: 0.8 (95% CI: 0.5-1.2/1.3)).

We also found that being immigrant (including first and second generation descendants) was negatively associated with home death (adjusted OR: 0.6 (95% CI: 0.4-0.9)) compared with ethic Danish children.

**Discussion**

Main findings

In this national study, we examined predictors for home deaths in a tax-financed and easily accessible health care system. Interestingly, we found that the groups of children with the highest household incomes did not seem to die more frequently at home compared to the least economically advantaged group. However, significant associations were found especially in relation to diagnosis and immigrant status. Moreover, a tendency was also found in relation to age, gender, region of residence and urbanicity.

Comparison with existing literature

We found that low household income is not associated with a lower probability of home death among Danish children. However, prior studies have found that low socio-economic position was associated with reduced odds of home death.7,11,12,15,21 The socio-economic position in those prior studies was calculated from either average area income or the Multiple Level of Deprivation Index and not for the specific household income as in the present study. Other differences are that in the present study, the tax-financed Danish healthcare system is universal and based on the principles of free and equal access to healthcare for all citizens.23 Furthermore, cultural differences between countries may have an influence which would have to be explored further.

Our finding that children dying from solid tumours tended to die more frequently at home than children dying from non-cancerous conditions is in line with many prior studies.6,10,14,15,21 The difference in place-of-death among children with different diagnoses probably mirrors the same trend among terminally ill adult patients, where different typical illness trajectories have been described for patients with cancer versus non-cancerous conditions.31 Embedded in this dilemma may also be the treating doctor’s mindset concerning children with non-cancerous conditions. Even though death is anticipated in childhood in these trajectories, it is not a visible ‘companion’ as in cancer trajectories. This may result in never planning the terminal phase and having end-of-life discussions in non-cancerous trajectories among children before it is too late32, and more deaths will thus take place at hospitals. This is also in line with our previous study where we examined indicators of high intensity treatment at end-of-life (HI-EOL).9 Compared with children dying from solid tumours, children with non-cancerous conditions had more than a 3-fold risk of having three or more indicators of HI-EOL at end-of-life. The trajectories leading to childhood death are heterogeneous and more knowledge of symptoms and illness trajectories is needed to manage and care more responsive and anticipatory when relieving illness burden and fulfilling preferences.33

We also found that children dying from solid tumours tended to die more frequently at home than children dying from haematological cancers, which was also found in other studies.11-13,18 In the above-mentioned review, we found that compared with children dying from solid tumours, children with haematological cancers had a 12-fold increased risk of having three or more indicators of HI-EOL in end-of-life.9 All in all it seems that haematological cancer trajectories among children has a different course, where anti-neoplastic and intense treatment is continued longer into the terminal phase than among children with solid tumours. This may be explained by the long-term survival rate for e.g., acute lymphoblastic leukemia being high and death due to treatment-related toxicities being nearly more common than death related to disease.34

We found that children of Danish origin had higher odds for dying at home than children of immigrant families. This was also a major factor in prior studies as ‘non-hispanic white’ children were found to be more likely to die at home than other children.12,16,19-21,32 It has been stated that some of this difference among ethnic groups may reflect socioeconomic inequality within groups.35,36 However, in the present study we adjusted for household income and we still found differences in place-of-death according to immigrant status. Gibson-Smith D et al comment on the little evidence on preferences of place-of-death in these populations and that differences in place-of-death possibly could be due to variance in access to healthcare services, cultural attitudes, or social support within the family.36 Furthermore, language difficulties and type of housing may be significant factors. Unfortunately, we did not have the opportunity to examine the above-mentioned factors.

As in prior studies, we found that lower age at death was associated with reduced probability of home death.12,14-16,18,19,21 However, age group cut-offs in the literature vary considerably, making comparison between studies difficult.9 From a previous study on a similar Danish populations of childhood deaths, we know that cause of death varies among age-groups.9 Among 1-4 yar old children only 10% died from solid tumors where e.g. 26% of 10-13 years old children died from solid tumors. Since there is a tradition on a focus on the possibility on home deaths among cancer patients thus may affect the rate of home deaths among the youngest age-group negatively. Also, the intensity of treatment may tend to be higher among small children giving them a higher probability to die at the hospital. However, this is merely speculations that has to be examined further in the future. There is no doubt that differences in diseases, trajectories and healthcare needs are extensive between early childhood and adolescence, which should always be taken into account.19,37

Region of residence and urbanicity seemed to be predictors for place-of-death in our study. In our systematic review from 2020, the meta-analysis on urbanicity showed no statistically significant difference between urban and rural areas in relation to place-of-death.7 In the present study, we mutually adjusted the two variables and found that children residing in the Capital Region had a lower probability of dying at home, but also that children living in the most urban areas were more likely to die at home. This means that outside the Capital Region, children living close to major hospitals may have better support to die at home. However, it has previously been found in two studies that long distance to hospital was associated with a lower probability of hospital death and intensive care admission at the end-of-life.13,19 Hence, the roles of urbanicity and region of residence are still unclear and may not be the generalised from country to country.

Strengths and weaknesses of the study

The primary strength of this study is the quality of the nationwide Danish registries, which provided a unique opportunity to investigate predictors in a setting with equal access to health care. However, this design has some limitations. Most importantly, we did not know the circumstances around the child’s disease and death, e.g., if the death was sudden or expected, if preferences of the family were clear or if symptom control was achieved. Furthermore, other factors that cannot be found in health care registers may be important: e.g. perception of quality of care amongst child and family, how dying at home is talked about with child and family and expected time and health care capacity required to start palliative home care.

We imputed place-of-death based on hospital admission status on the date of death in 40 cases because of missing data. Due to the high validity of registry data, we believe this method is acceptable.38

As described above hospice deaths were unfortunately categorised as hospital deaths in the data. However, the first Danish paediatric hospice stated in their 1-year report that only four children had died at the hospice in the period of 1 November 2015 to 31 September 2016.Hence, it is a small number of children that die at hospice, and since they are included in the group of hospital deaths, they do not alter the predictors for home deaths.

We only included children between one and 18 years of age. However, more than half of the children in our initial population died before one year of age and were therefore excluded. This may be a limitation, but it was done to eliminate some of the heterogeneity we inevitably see in the trajectories among terminally ill children.

Despite the limitations mentioned above, we believe that this study provides important insights into the disparities in place-of-death among children between one and 18 years of age.

Implications for future research and clinical practice

The best quality of death for children should always be pursued no matter the place-of-death, by optimising symptom relief, preparedness, support and comfort.(WHO)Some has even suggested that the opportunity to plan end-of-life may be a better proxy for high-quality end-of-life care than the actual place-of-death.39 However, it is still puzzling why the rate of home death among children varies extensively between subgroups concerning diagnoses and ethnicity and focus on different preferences, terms and conditions is warranted in clinical practice and in research.

A special focus should be on the children at risk of dying in hospital and maybe especially in intensive care units, where transfer to die at home is often hard and complex.40 It is recommended to examine global and local barriers and facilitators to meet families’ preferences for home death.

**Conclusion**

We found that household income was not associated with dying at home among children in Denmark. We believe this is because of the Danish tax-financed, equal-access health care system. However, having a haematological cancer, a non-cancerous diagnosis, being an immigrant or living in a rural area were associated with lower odds for home death. Cultural differences in both professionals’ palliative approach, in the mindset of families as well as the heterogeneous illness trajectories may partly explain the differences and should be considered in the clinical setting and further investigated.

**Conflicts of interest/Competing interests:** The authors disclose they have no potential conflicts of interest.

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