

# The importance of specialized palliative care on pediatric cancer patients' choice of place of death

*6<sup>th</sup> Maruzza International Congress on  
Paediatric Palliative Care 2024*

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# Background

## Childhood cancer:

- Childhood cancer diagnosis  $n = 200$  each year in DK.
- 5-year survival rate at approximately 89%.
- Relapse or progression of their disease.
- Cancer remains a significant contributor to pediatric mortality.

# Background

## **Palliative Care:**

- Establishment of five regional specialized Pediatric Palliative Care Teams 2015 - 2017
- Combine specialized treatment
- Quality of life
- Fulfilling individual wishes

# Aim

In this retrospective cohort study on children (age 0-18 at death) with advanced cancer, we wished to examine the effect of implementing a specialized Pediatric Palliative Care Team in Denmark to provide optimal end-of-life care. Specifically, we wanted to evaluate the effect of the implementation on;

- i) the preferred place of death,
- ii) the actual place of death,
- iii) and the concordance between the two before and after the implementation.
- iv) Lastly, to evaluate which and how determinants influence the child's preferred place of death.

# Methods

## Study design:

- A single-center retrospective comparative cohort study.
- Data collection from August 2023 to April 2024 via journal review

## Patient group:

- Pediatric cancer patients who passed away between 2002 and 2023
- Patients <18 at the time of death
- Receiving end-of-life treatment for their malignant disease at HCA, OUH

The Pediatric Palliative Care Team at HCA, OUH was established in September 2016.

- 25 pediatric cancer patients from the establishment till the end of the study period
- Compared to historical controls, 63 patients from the time between 2002-2016
- 88 patients total

# Methods

## Data collection:

- Demographic data, diagnosis details, and information regarding death
- Preferred was categorized as home, hospital, hospice, or ‘not considered’ if no clear preferred place of death was documented in the patient file.
- Actual was categorized as home, hospital, or hospice.

# Baseline characteristics

<b>Factor</b>	<b>Category</b>	<b>Total</b>	<b>After the Pediatric Palliative Care Team</b>	<b>Before the Pediatric Palliative Care Team</b>
<b>N</b>		88	25	63
<b>Gender</b>	F	48 (55%)	16 (64%)	32 (51%)
	M	40 (45%)	9 (36%)	31 (49%)
<b>Age at diagnosis, median</b>	Years	6	6.9	5.8
<b>Relapse</b>	NO	36 (41%)	12 (48%)	24 (38%)
	YES	52 (59%)	13 (52%)	39 (62%)
<b>Diagnosis Group</b>	Leukemia/Lymphomas	25 (28%)	4 (16%)	21 (33%)
	CNS	39 (44%)	14 (56%)	25 (40%)
	Solid tumors outside of CNS	24 (27%)	7 (28%)	17 (27%)
<b>Age at death, median</b>	Years	9.5	11.5	8.6
<b>Duration of disease, median</b>	Years	1.4	1.8	1.3

# Results

## Wishes expressed:

The total of patients expressing a preferred place of death was 46% before nearly doubling percentage-wise to 84% (p-value 0.002).

## Preferred Place of Death:

	<b>Before the Pediatric Palliative Care Team</b> n = 63	<b>After the Pediatric Palliative Care Team</b> n = 25
<b>Home</b>	24 ( <b>38%</b> )	16 ( <b>64%</b> )
Hospice	0 (0%)	3 (12%)
Hospital	5 (8%)	2 (8%)
'Not considered'	34 (54%)	4 (16%)



# Results

## Actual Place of Death:

	<b>Before</b> the Pediatric Palliative Care Team n = 63	<b>After</b> the Pediatric Palliative Care Team n = 25
<b>Home</b>	24 (38%)	15 ( <b>60%</b> )
Hospice	0 (0%)	2 (8%)
<b>Hospital</b>	39 ( <b>62%</b> )	8 (32%)

## Concordance:

Concordance significantly increased from **38%** (n=24/63) to **68 %** (n=14/25) (p-value 0.011).

Primary analysis resulted in a significant odds ratio of 3.77 (p-value 0.028)

# Explanations

Might be a multifactorial

- A more streamlined approach by the team
- More cohesiveness between cross section processes
- Simply the resources being available
- Education to handle death at home

But more children get to voice their preferred place of death, and these are documented.

Which must be the first step to fulfill them.

Wishes mostly at home.

# Explanations

## Strengths:

- Full follow-up time diagnosis till death
- Long study period on both sides of the implementation

## Limitations:

- The difference in cohort sizes before and after 63 vs. 25
- Many ‘not considered’
- The option of hospice for children 2015 + 2020

# Conclusion

**This study shows that implementing the Pediatric Palliative Care Team has helped secure a better concordance with the child and family's wishes regarding the place of death.**

- 1) Significantly more children become aware and get to express their preferred place of death nearly doubling percentage-wise.
- 2) When dialog of preferred place of death was documented, there were significantly higher odds of dying at home (OR 18.76 p-value < 0.005).
- 3) Concordance between the preferred and actual place of death improved significantly.

With the likelihood increasing of getting, one's preferred place of death as one's actual post-implementation.

# Acknowledgements

Funding for the project is thanks to grants from mainly Børnecancerfonden, but also A.P. Møller Fonden.



**Questions?**



OUH  
Odense Universitetshospital  
Svendborg Sygehus

