

Palliative Care for Children



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Pediatrician

Lilla Erstagården
children's and
youth hospice



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Lilla Erstagården barn- och ungdomshospice



The only children's and
youth hospice in Sweden

Ersta diakoni,
a non-profit organization,
but financed by
SLL (Stockholm county)

5 patients/families

Children and youth 0-18 yr



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Palliative Care for Children



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Palliative Care for Children



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Palliative Care for Children

Are there any differences between pediatric and adult palliative care?

or

Are there more similarities than differences ?

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Palliative Care

Family centered care
with the patient in the center

*"Live as good as possible
for as long as possible"*

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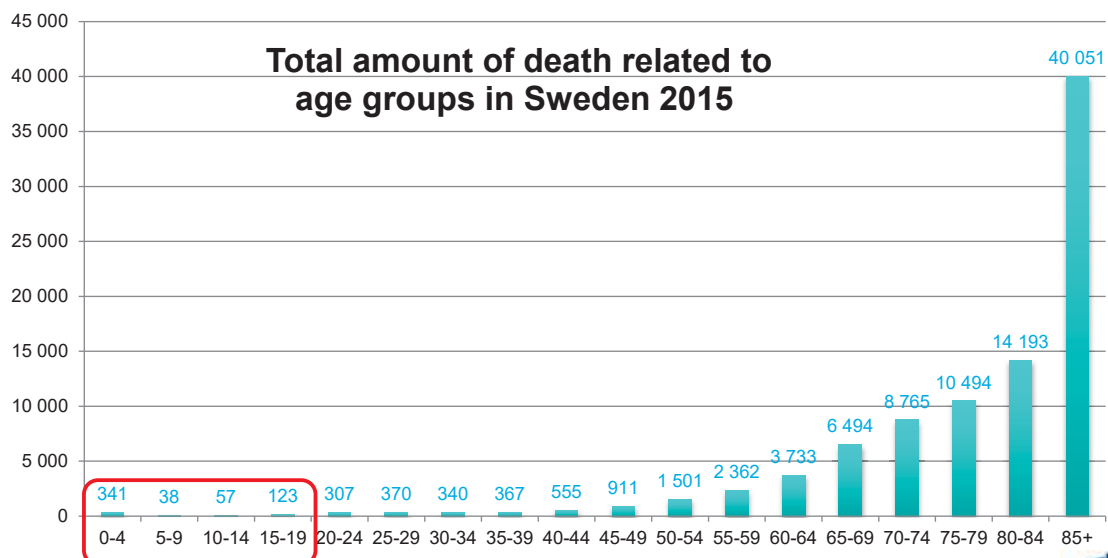
Palliative Care for Children and Youth

Palliative Care for Children, Youth and Young Adults



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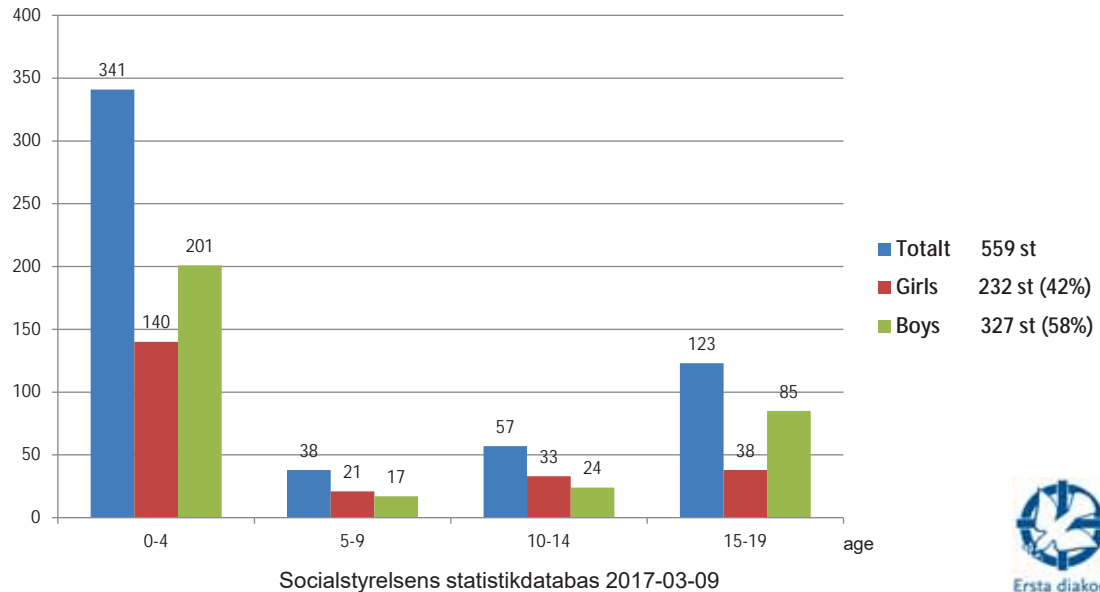
Who dies?



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How many children die?

Total amount of death less than 19 yrs related to age group and gender in Sweden 2015



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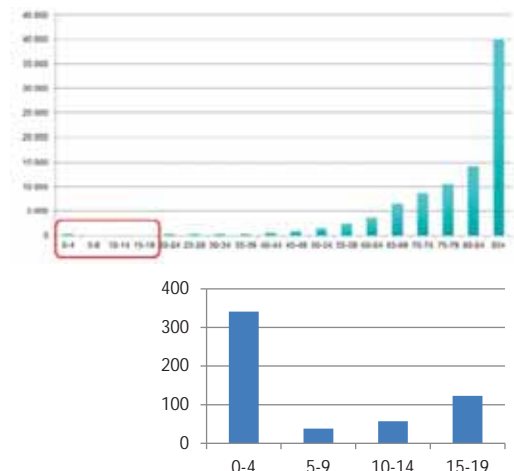
So few children - why bother?

- 559 children less than 19 yrs old out of 91 002 deaths

BUT

A death of a child is a loss

- that is "unnatural"
- that is uncommon
- that affects many
- that affects for a long time
- of expectations and a hope of a future



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Palliative Care for Children

- Parents to young patients/children are usually more directly and actively involved in the care than the relatives of an adult patient in palliative care
- It's important to keep in mind the needs of the siblings
- The death of a child could also have a strong effect on health professionals



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I'm never going to do this!!!

Well maybe but

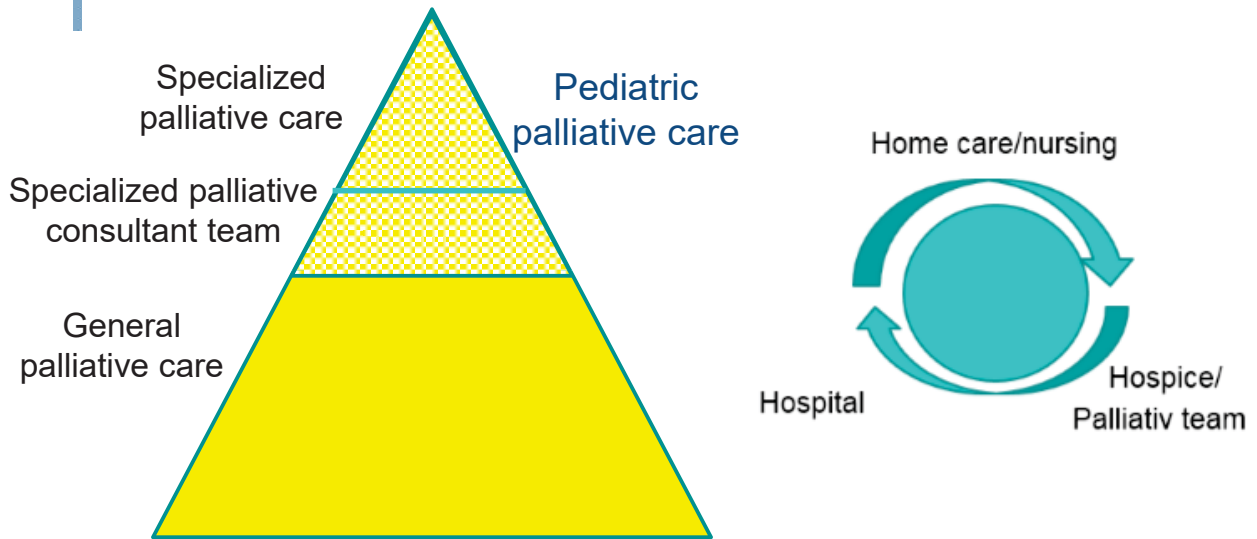
- It's a growing field – a need of more knowledge!
- The further from a regional center you work the more you might/should be involved?
- Children have the same right as adults to a good palliative care where ever they live

– so maybe you should be doing this!



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Let's do this - but together

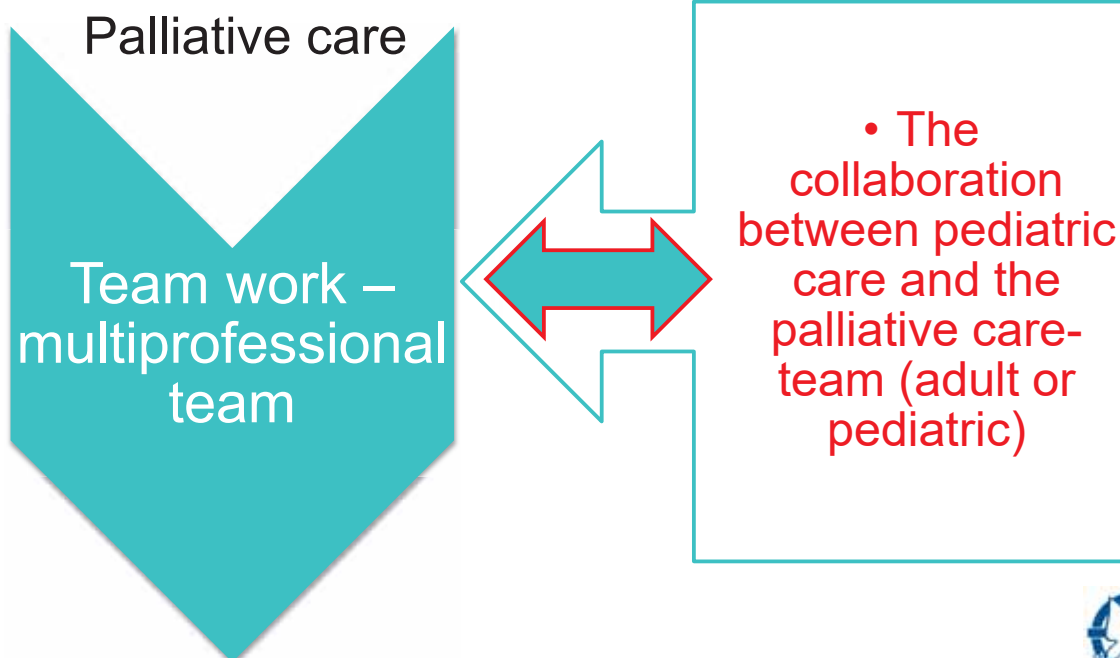


It happens seldom – **we as pediatricians need your expertise in palliative care !**



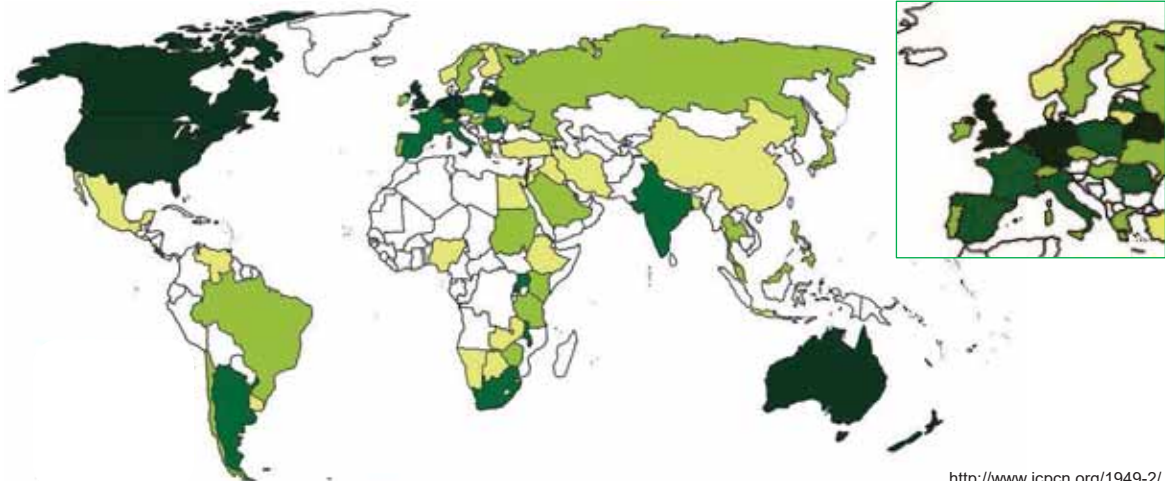
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Collaboration



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Palliative Care for Children in the world



Integrated	Dark Green	Evidence of broad palliative care provision for children. Approaching full integration within health care services as well as a national policy to support children's palliative care.
Broad provision/education program	Medium Green	Evidence of broad palliative care provision for children with training available and focused plans for development of services and integration into health care services.
Localised care/hospice/training	Light Green	Evidence of localised palliative care provision for children and availability of training.
In a set up phase	Yellow	Evidence of capacity building activities for the provision of children's palliative care.
None	White	No known provision of children's palliative care.

<http://www.icpcn.org/1949-2/>



Palliative Care for Children in Sweden



Stockholm
Sjukhusansluten
avancerad barnsjukvård
i hemmet
(SABH)
and
Lilla Erstagården
24/7

In the rest of the
country pediatric
hospital units and
adult homecare



Network for Palliative Care for Children in Sweden

Purpose:

- A multi-professional network to gather the existing knowledge and competence in pediatric palliative care in order to make it better and more equal for the child and family
- To work towards at multi-professional national education in palliative care for children in Sweden
- Sharing knowledge

Contact person christina.lindstrom@erstadiakoni.se



Palliative Care for Children

Children are not young adults



According to the UN Convention on the Rights of the Child - every humanbeing under the age of 18 years a child





Palliative Care for Children

UN Convention on the Rights of the Child (CRC)

- The best interests of the child shall be a primary consideration
- The child is of no less value than adults
- The child is vulnerable and in need of support and protection.
- The child's opinion should be considered in regards to its age and maturity



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<http://www.nobab.se>

**Nordic network
for children's
rights and
needs in health
care**



en vän när barn är sjuka



WHO Definition of Palliative Care for Children

- An active total care of the **child's body, mind and spirit**, and involves giving **support to the family**.
- It **begins when illness is diagnosed**, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.

<http://www.who.int/cancer/palliative/definition/en/#>



WHO Definition of Palliative Care for Children

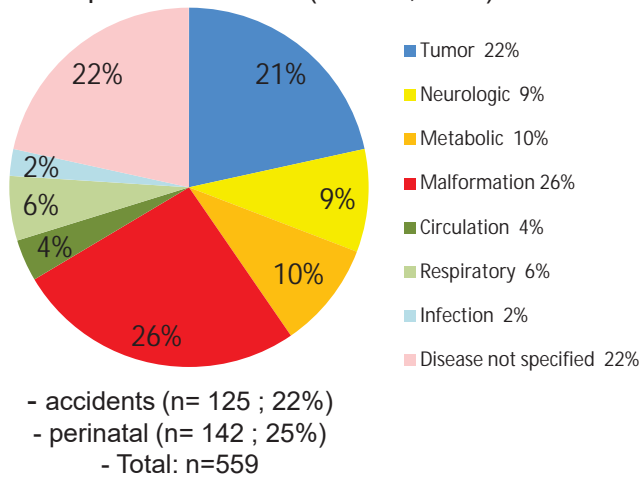
- Effective palliative care requires a **broad multidisciplinary approach that includes the family** and makes use of available community resources;
It can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers and even in children's homes.

<http://www.who.int/cancer/palliative/definition/en/#>

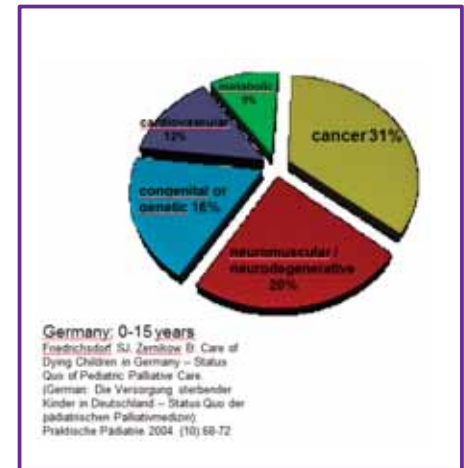


Causes of death in children

Causes of death in children
0-18 yr old in Sweden 2015
excluding accidents
and perinatal deaths (n=292 ; 53%)



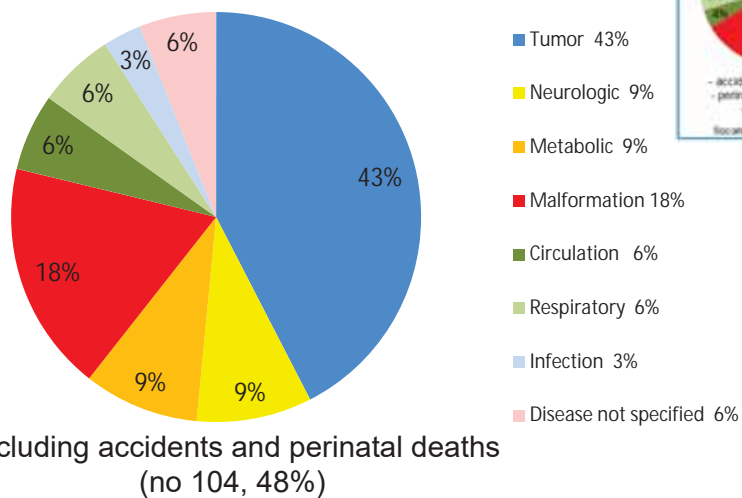
Socialstyrelsens statistikdatabas 2017-03-09



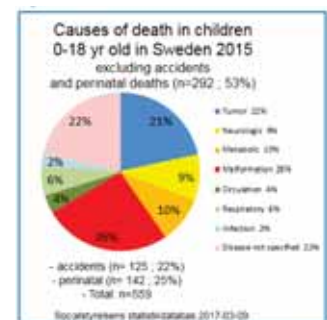
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Causes of death in children

Causes of death in children 5 - 18 yr
in Sweden in 2015 (n=114 ; 52%)



Socialstyrelsens statistikdatabas 2017-03-09

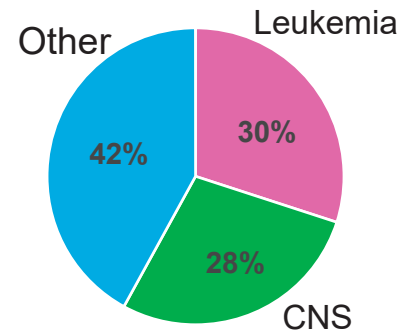
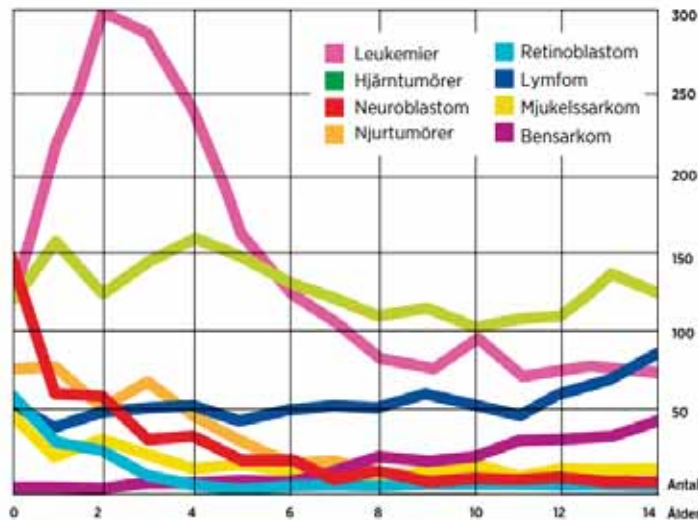


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What typ of cancer in childhood

ÅLDER VID INSJUKNANDE I OLIKA TYPER AV CANCER

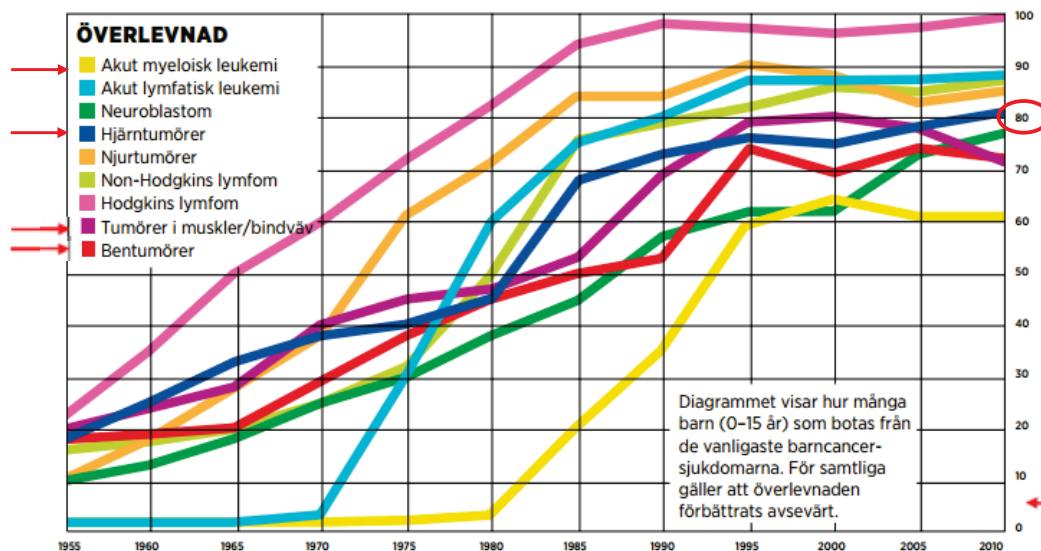
Diagrammet visar åldersfördelningen för de vanligaste cancerformerna för barn.



"Cancer hos barn och tonåringar". Barncancerfonden

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From death to a survival rate of 80%



Diagrammet visar hur många barn (0-15 år) som botas från de vanligaste barncancer-sjukdomarna. För samtliga gäller att överlevnaden förbättrats avsevärt.

Pons-tumör

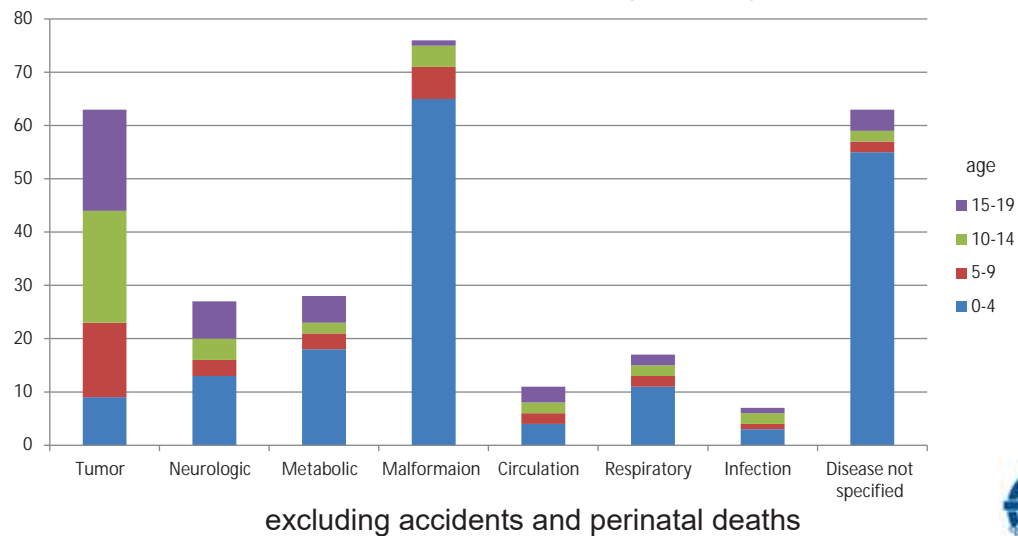


"Cancer hos barn och tonåringar". Barncancerfonden

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Children in need of palliative care?

Causes of death in children by age groups 0-18 yr in Sweden in 2015 (no 292)



Socialstyrelsens statistikdatabas 2017-03-09



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Groups in pediatric palliative care

1. Life-threatening conditions for which curative treatment may be feasible but can fail – **palliative care alongside with curative care.**
2. Conditions where **premature death is inevitable** but there might be **long period intensive treatment aimed at prolonging life with normal activities**
3. **Progressive conditions with no curative treatment** – maybe palliative for many years
4. Irreversible but non-progressive conditions, likelihood of complications leading to premature death

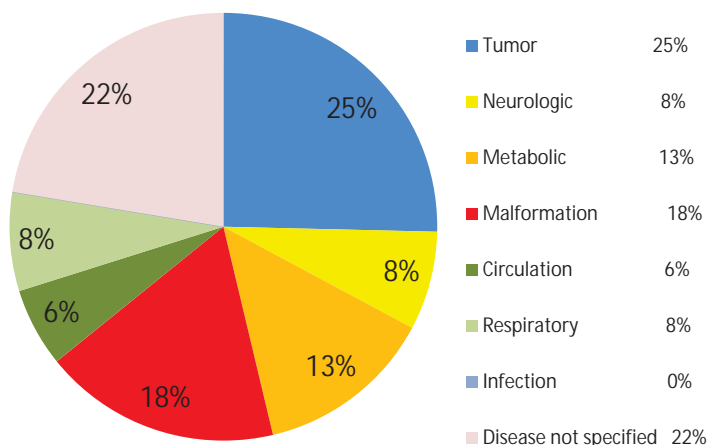
Craig F, Abu-Saad Huijjer H, Benini F, Kuttner L, Wood C, Feraris PC, et al. [IMPACT: standards of paediatric palliative care in Europe]. Schmerz. 2008 Aug;22(4):401-8.



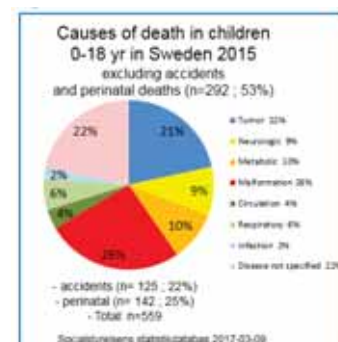
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Deaths in Stockholm

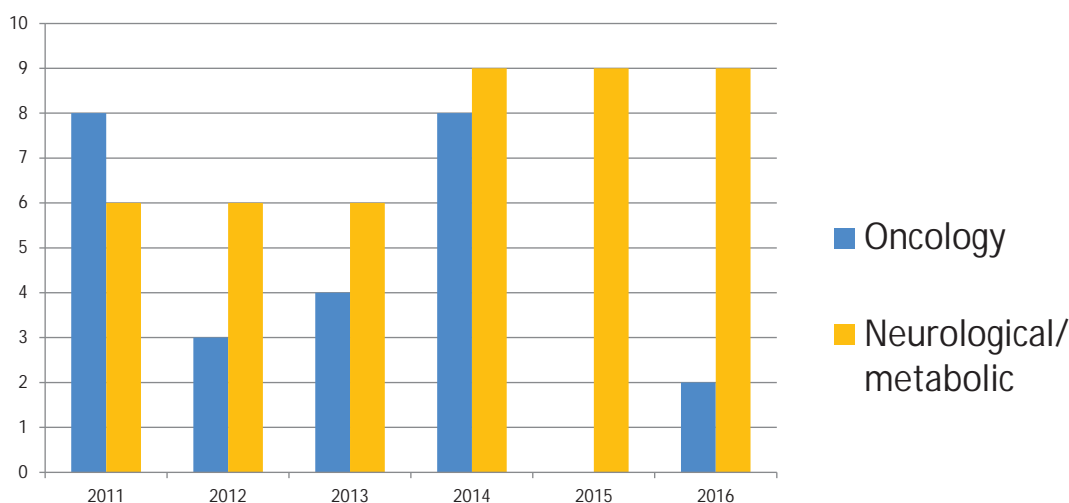
Causes of death in children
0-18 yr (no 67)
in Stockholm in 2015



Without external causes and
perinatal deaths



Groups of patients at Lilla Erstgården



In pediatric home care in Stockholm
almost the opposite numbers



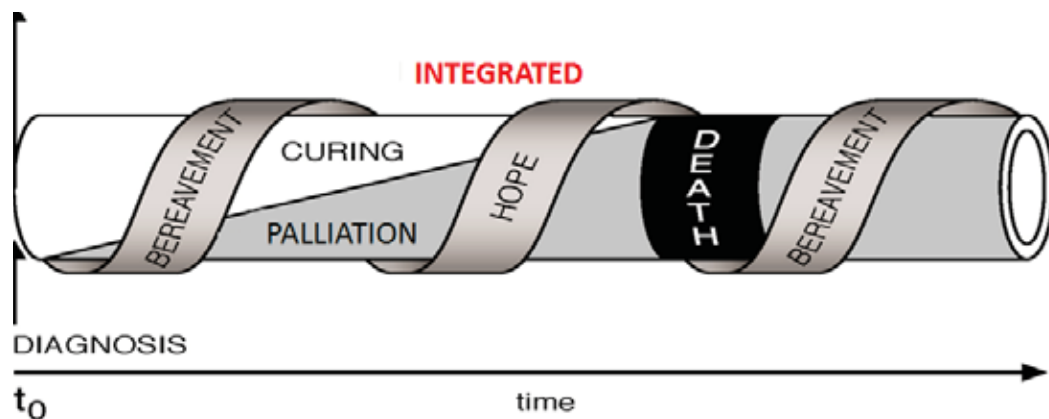
Palliative Care for Children

- The palliative care can take many ways
 - a few days
 - months to many years
 - and can look very different



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Integrated Palliative Care



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Palliative Care for Children

- Serious disease where there is a risk they may not reach adulthood
- Palliative care and curative treatment can be given at the same time

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Cornerstones in palliative care



Relief of symptoms –
physical, psychological, social and existential needs

Multi-professional team

Communication and relations to further the patient's quality of life by means of **good communication** and relations within and between the team of professionals and the relation to the patient, the family and relatives

Support of family and relatives - during the illness and following the patient's decease



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Art, music and play therapy

No evidence based studies to evaluate the benefits of art, music and play therapy on children's wellbeing and quality of life but there are many case studies that shows the positive experiences of art, music and play therapy in pediatric palliative care



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Sibling supporter

- 75 % - two pediatric nurses share
- Both oncology and neurology patients
- Both activities and support groups



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- The illness, treatment and prognosis could be **perceived very differently** between the parents, the health care team and the child
- There are differences in ethical and legal aspects, as **the level of autonomy**

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How to decide the level of autonomy?

Treatment by force is not allowed in any of the Nordic countries

- A consent is needed for treatment
- A caregiver can however for younger children give a consent for treatment against the will of the child
- The child's level of autonomy

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How to decide the level of autonomy?

It differs between the Nordic countries

BUT

The physician should always make a evaluation of maturity and with increasing age and maturity the childs codetermination should increase and in some situations pass into self-determination/ autonomy



Palliative Care for Children

How to decide the level of autonomy?

It differs between the Nordic countries

- Norway has the laws with most details then Denmark, Sweden and Finland
- Norway, Denmark and Finland have age limits
- Sweden have no age limit, but an evaluation of maturity



To talk about death with your child?

Kreicbergs U., et al. Talking about Death with Children who Have Severe Malignant Disease. N.Engl.J.Med. 2004;351(12):1175-86.



Palliative Care for Children

Remember

- The child can have different ways of communicating their needs than adults.
- How the child communicate can be depend on the leavel of maturity which is not always correlated to age.
- It's important that health professionals have knowledge and competence in communication with children



Palliative Care for Children



- Communication through books, movies, games ...



The leap of faith...

- With questions you might not hear or understand if you are not attentive



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Existential questions

- Will I die?
- What have I done to deserve this?
- Why me?
- What happens after I die?
- Why is mom and dad so distressed?
- Can I breathe in the coffin?
- Can I have a soft drink when I'm with God?



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Children's understanding of death at different ages

0-3 yr

0-1 yr no concept of death. Gradually death becomes equal to absence. The child can feel fear of being separated from its parents and is afraid of being harmed. The child cannot think abstract thoughts.

4-6 yr

Death is equal to not moving, "Bang, you're dead- Now you get up and play again". Death is not permanent and can be repaired. The child may not understand that death can happen to all of us.

7-9 yr

The child has begun to understand what death is but has many misconceptions. Death has always a reason and could be caused by something the child has done.



Children's understanding of death at different ages

9- 12 yr

Death is more realistic, the child can now understand that old people can die but also young people may die. Death is now forever and when you die you can't come back. Children can have great concern about their parents. Existential thoughts with reactions like great anxiety or maybe very calm.

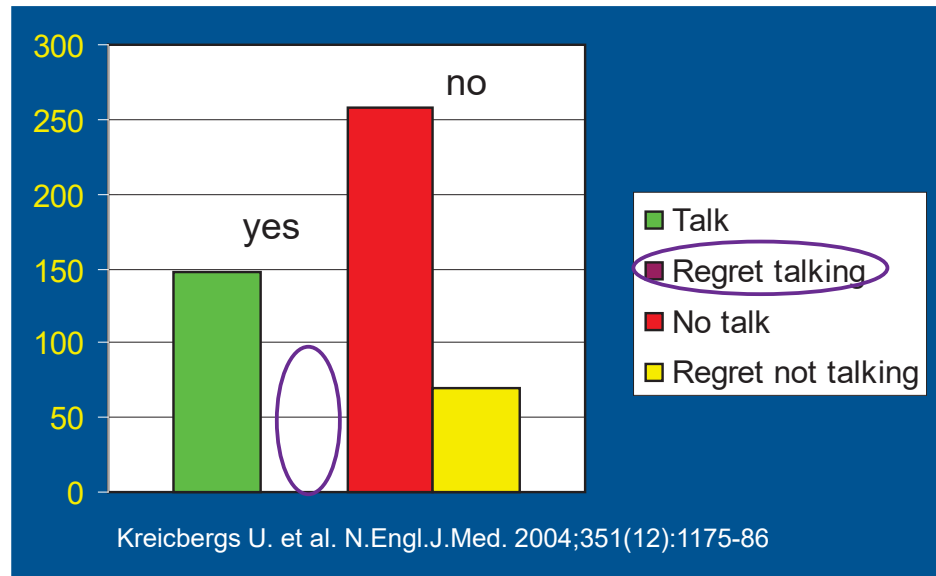
Teenages

They are now able to intellectually understand death and may see it as unfair and a punishment. It's a threat to their life and their future. Anxiety of death with existential suffering.

There is a great overlapping between the groups depending on maturity level.



No parent regret talking



Talking about death with your child - yes or no?



What does the child want?

ACTA PÆDIATRICA

Acta Paediatrica ISSN 0803-5253

REGULAR ARTICLE

Children with cancer share their views: tell the truth but leave room for hope

Li Jönell^{1,2}, Malin Löfgren^{3,4}, Ulrika Kreicbergs^{5,6}, Jan-Inge Henter^{4,6}, Britt-Marie Frost (britt-marie.frost@kth.se)^{5,6}

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⁵Department of Pediatrics, Uppsala University Hospital, Uppsala, Sweden

Key notes

- This study of children with cancer explored what they regarded as important when they received bad news.
- Interviews with 10 children aged seven to 17 years revealed that the children wanted bad news to be delivered truthfully, but as positively as possible, so that they could maintain hope.
- They also said they wanted to be informed at the same time as their parents and in words that they could understand.

ACTA PÆDIATRICA

Acta Paediatrica ISSN 0803-5253

EDITORIAL

Abby R. Rosenberg^{1,2,3}
Chris Feudtner (Feudtner@email.chop.edu)^{4,5}

DOI:10.1111/apa.13510

What else are you hoping for? Fostering hope in paediatric serious illness



What does the child want?

The youth and the child want honest information first hand or together with their parents.

Yet, give hope !

- for different things



How do you give up on your child?

When do you give up on your child?



Is disease specific treatment more difficult to give up in a child?

When ? - many similarities with adults

- Risk of damage of treatment
 - Side effects
 - Poor quality of life
 - "Wrong" focus
 - Shorten the chance of survival



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Is disease specific treatment more difficult to give up on a child?

When ?

- The patient says no ? – level of autonomy has to be considered
- Treatment have no positive effect/ give more damage than benefit
- The patient is too ill to cope with the side effects/ examinations/ treatment
- Too short predicted survival to benefit from the treatment



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Is disease specific treatment more difficult to give up on a child?

When ? - have similarities with adults

but

How can you decide on when to end the disease specific treatment of a child – your child?



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Communicating with children and families about integrating palliative care

- What do the parents/child know about the situation and the care given?
- What have they been told/heard/understood?
- To find and define the goal of the care
- Talk about the possibility of death ("plan A /plan B")



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Communicating with children and families about integrating palliative care

- Important with hope and a firm relation with the child and the family
- Introducing palliation
- Talk about what to expect, if possible make written plans if/when symptoms/complications
- Try to talk to/with the child – the adult might then understand even better



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REMAP conversation to define the goal of care

- **REFRAME** - reframe why current status is not working- similar to "bad news conversation"
- **EMOTION** Emotional response might sound like a question – don't answer but acknowledge
Ask permission before moving on
- **MAP OUT WHAT'S IMPORTANT** identify the families/patients goals and values – ask don't guess!
- **ALIGN WITH PATIENTS VALUES** repeating what you have been told and make sure you understood
- **PLAN TREATMENTS THAT MATCH VALUES**
- give recommendations and make a plan



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