



The time remaining” – Palliative Medicine and School

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Paediatric palliative medicine in the LMU Clinic in Munich

WHO Definition: Paediatric palliative care (1)

“The palliative care of children includes the active care of physical, psychological and spiritual needs of a child and its family from the point of diagnosis...

Definition by WHO 1998

Paediatric palliative care (2)

...Effective palliative care requires a multidisciplinary approach involving the family and taking advantage of available regional support services.”

Ca. 3,000 children die every year in Germany from life-shortening illnesses

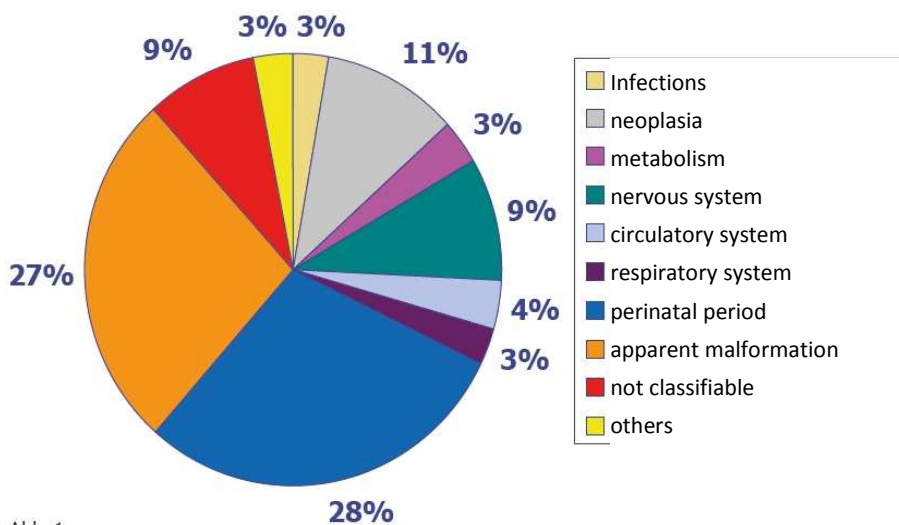


Abb. 1

Causes of death in children below the age of 20 (Bavaria 2005, n = 602)

When does the palliative phase begin?



Kausale Therapie

Palliative Therapie

“We need a system that integrates palliative care with curative treatment“

Dabbs D, Butterworth L; MCN 2007



Preschool as Palliative Care

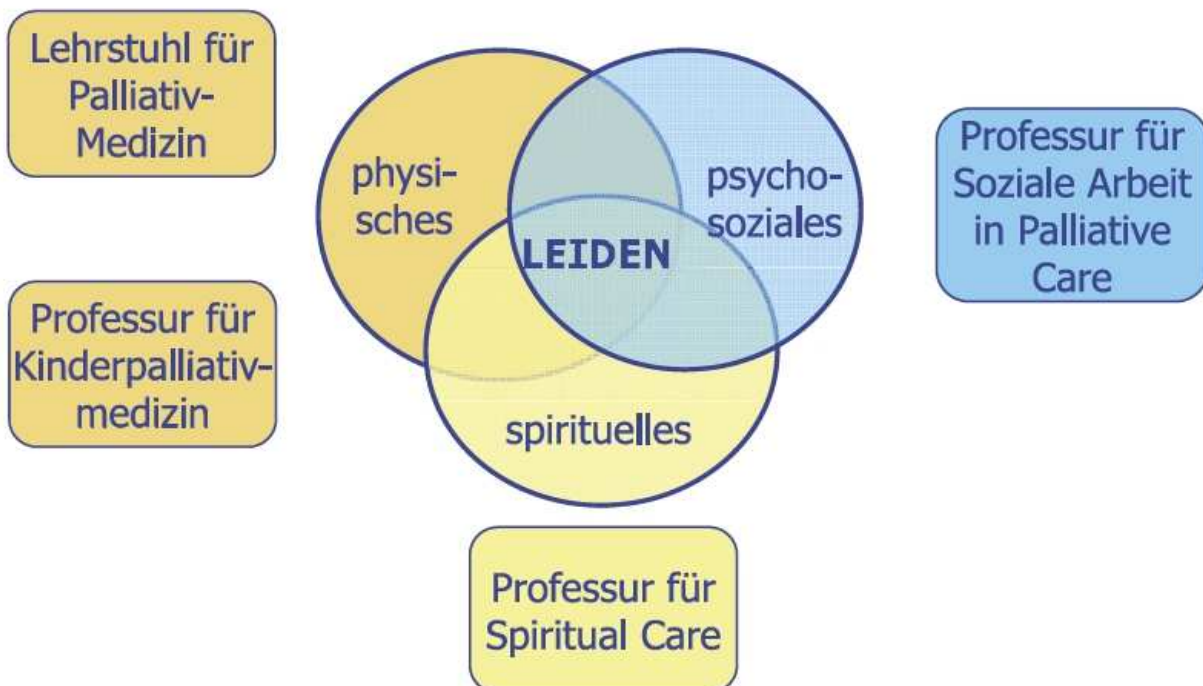
M.E. Ross, J. Hicks, W.L. Furman *J of Clinical Oncology* 26(22), 2008

One privilege of caring for children with cancer is witnessing the courage with which families face life despite the disease.

Therapeutic objectives

- Healing
- Extension of life
- Rehabilitation
- Functional improvement
- Alleviation of pain
- Improvement of quality of life
- Enabling of "good death"

Palliative medicine at Ludwig Maximilians-University, Munich



Quotation

„We would so like to be at home together with our child and the whole family, but we are afraid of doing something wrong.“

Mother of dying 3-year-old child



What are the greatest obstacles for parents?

- Burden of responsibility
- Exhaustion
- Fear of serious symptoms and suffering
- Fear of being alone in a crisis
- Fear of damaging the child and shortening his or her life
- Uncertainty of when to expect death of child
- Unsettling thoughts about death

“How will our child die?”

Needs of children and their families

- Reliability in the control of symptoms
- Round-the-clock availability of support team
- Alleviation of suffering of patient and family
- As much time as possible together with family
- Privacy sphere: if possible through care at home
- Reliable network of care at home
- Avoidance of social isolation and participation in life

Special requirements for children. In paediatric palliative care:

- Age and stage of development determine communication and interaction
- Parents, brothers and sisters and the familiar social environment are vital
- Concepts of illness and death are dependent on age and stage of development
- Participation in normal child activities (kindergarten and school) has therapeutic significance

What are the greatest obstacles for helpers?

- Insufficient time
- Lack of knowledge and experience
- Lack of cooperation
- Lack of clear structures and responsibilities
- Insufficient information and communication
- Insufficient support (finance, advisory services)
- Insecurity concerning legal stipulations

Requirements for helpers

- Reliable information flow between care structures (in- and outpatient)
- Coordination of medical prescriptions and various helpers



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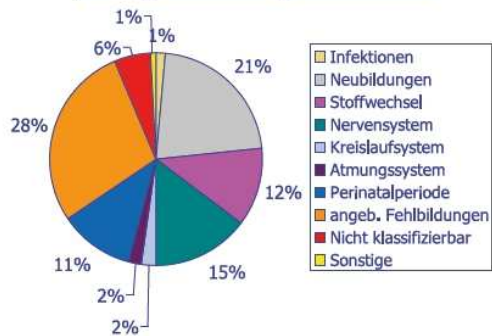
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- Consultation between care team regarding control of symptoms
- Organisation of debriefing conference following death of child

The project HOME

Between March 04 and October 09, more than 220 children and adolescents with life-shortening diseases were seen by the coordination unit Paediatric palliative medicine at the University Clinic in Munich

Diagnosespektrum



Patientencharakteristika

Geschlecht	47% Knaben
Migrationshintergrund	25%
Alter (Median)	5 Jahre (7d – 43 J.) < 1J. n=31 > 18J, n=12
Perinatale Betreuungen	10
verstorben	118

HOME - Hospiz ohne Mauern



(HOME - hospice without walls

Network for paediatric palliative care in Bavaria

Working party Paediatric Palliative Medicine

- First session April 2003
- Interdisciplinary and multi-professional
- 40 sessions in two-monthly rhythm already held

Working group Paediatric palliative medicine in Bavaria

- Established 2006
- All palliative care initiatives in Bavaria



- 10 sessions in twice-yearly rhythm already held

In-house training course: participants

	n	Berufserfahrung in Jahren MW (range)
Teilnehmende gesamt	134	10,6 (0,5-37)
Pflegende	95	10 (0,5-37)
Ärzte	21	11 (1,5-30)
Physiotherapeuten	8	11 (0,5-22)
Sozialpädagogen	7	14 (1-30)
Lehrer	2	9 (5 – 12)
Seelsorger	1	9 (3-15)

Tasks of coordination unit Paediatric palliative medicine (KKiP)

- Preparation of discharge for going home
- Coordination of palliative care at home
- Advisory service for parents and helpers
- Support for communication between helpers
- 24/7 tel. on-call service of specialist paediatricians
- Support following death of child
- Debriefing conference for local care teams

Listening, listening, listening, listening

Preventive function

Support of family in dying and grief phases helps:

- Preserves family bonds
- Avoids mental disorders in parents
- Helps siblings during the processing of their loss and...
- ... supports their healthy mental and physical development

Evaluation: support for siblings

Patients with siblings 63%

Deceased siblings 16%

Sick siblings 8%

Advisory services for parents 42%

Therapeutic intervention 18%



> "The team is fully occupied with the needs of the sick child!"

Multi-professional care network

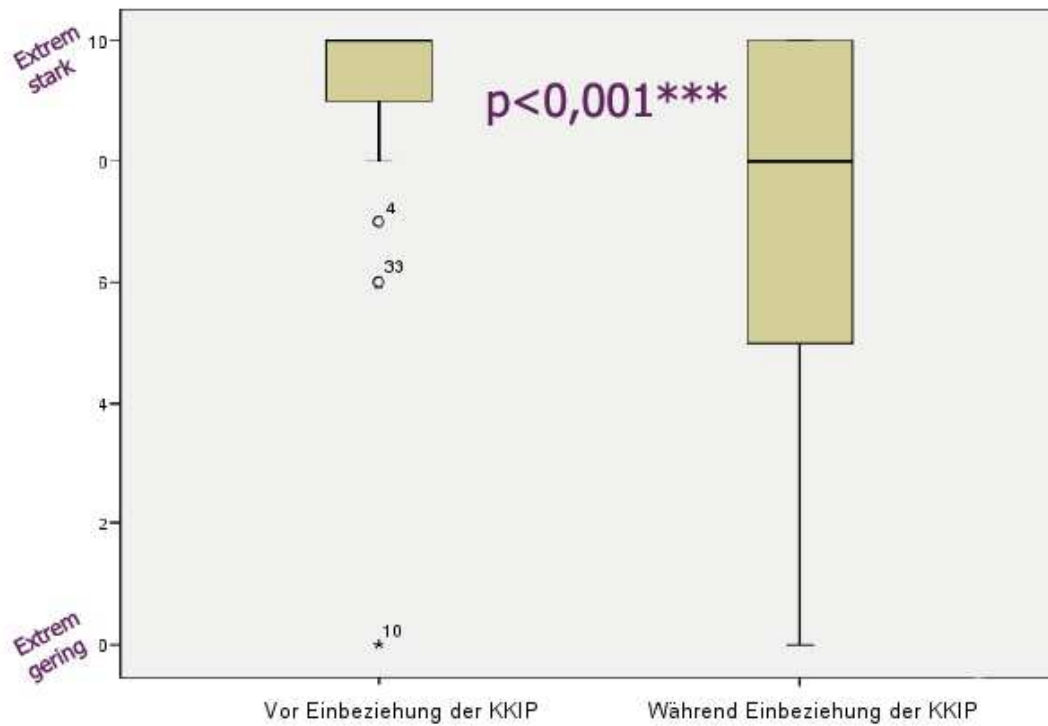


Pilot study on quality of care in paediatric palliative medicine

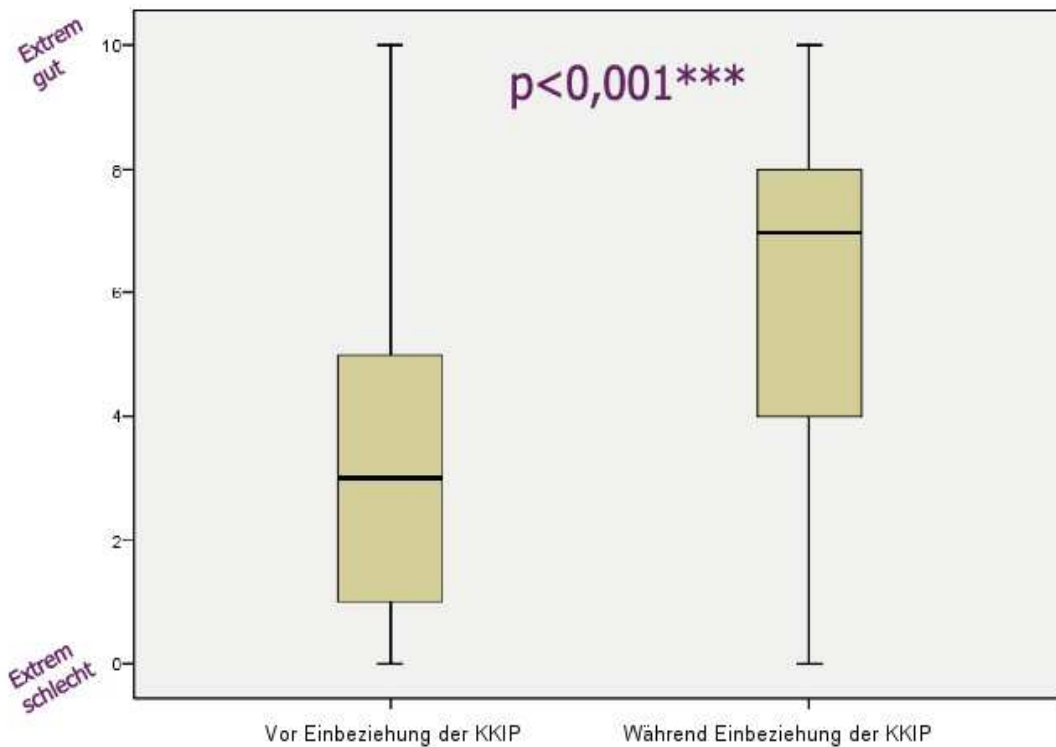
Rene Vollenbroich, Ayda Duroux, Monika Brandstätter, Gian Domenico

Borasio, Monika Führer

Strain on parents through child's symptoms



Quality of life of child (parents' evaluation)

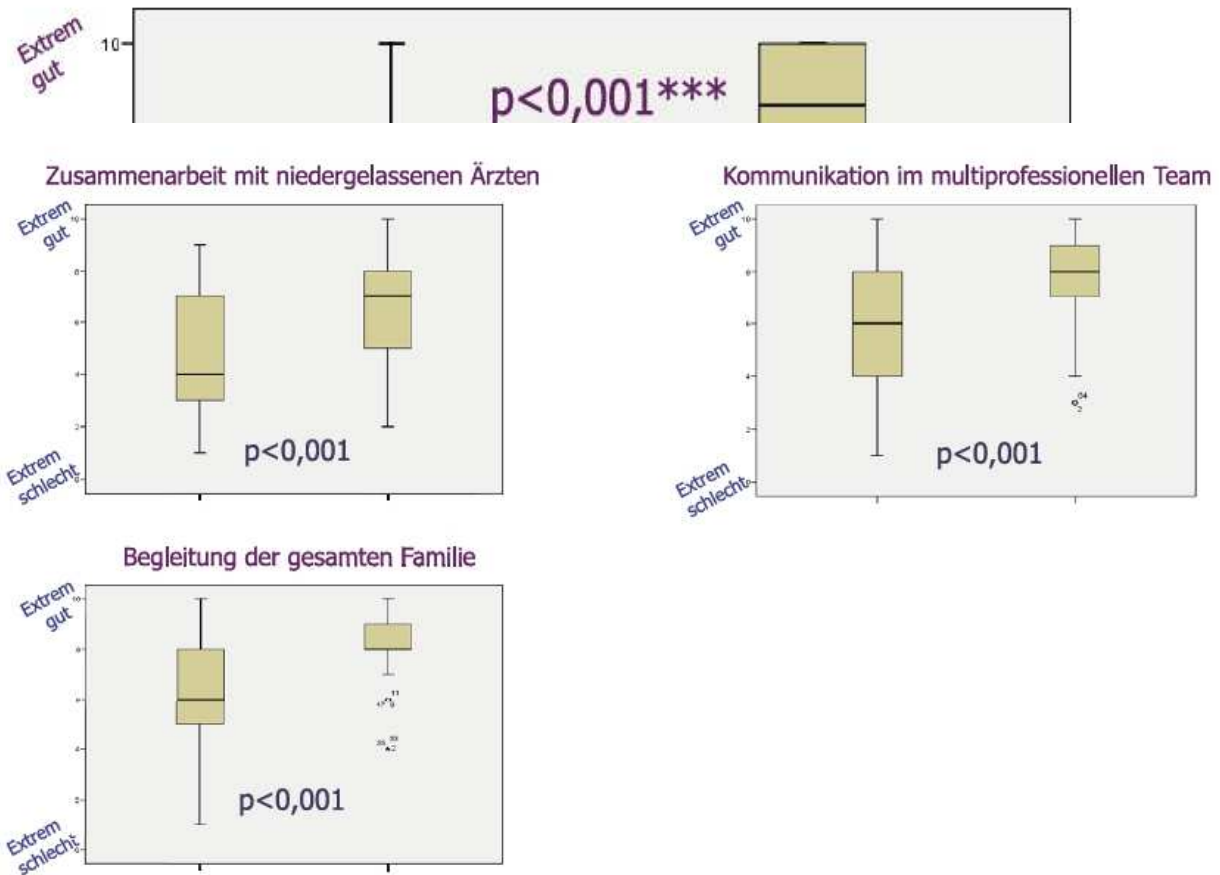


Communication between helpers in local care team

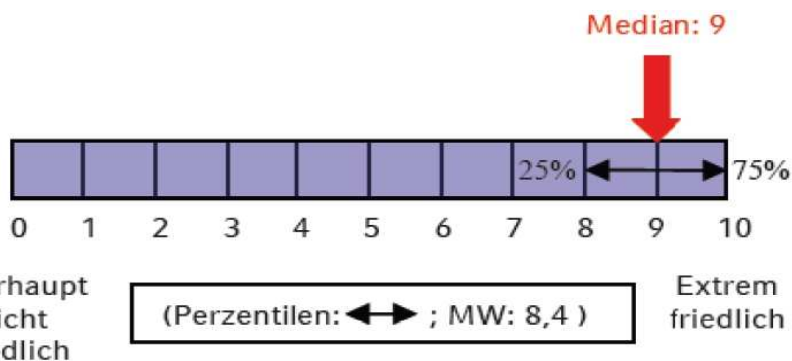


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Project HOME
 Improvement of quality of care:
 Survey of helpers
 Evaluation of satisfaction of professional helpers



(n=105; doctors 51%, other care staff 27%, 22%) before and after care through KKiP

Progress of dying phase – evaluation of parents

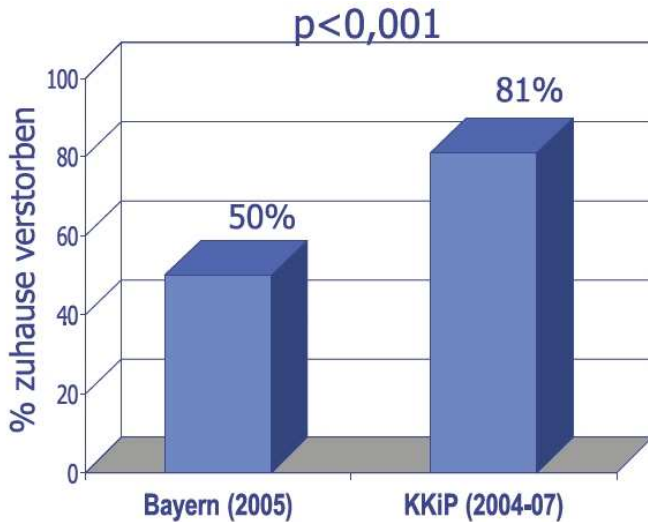


good place to die: 37/38 yes (71.1% at home)

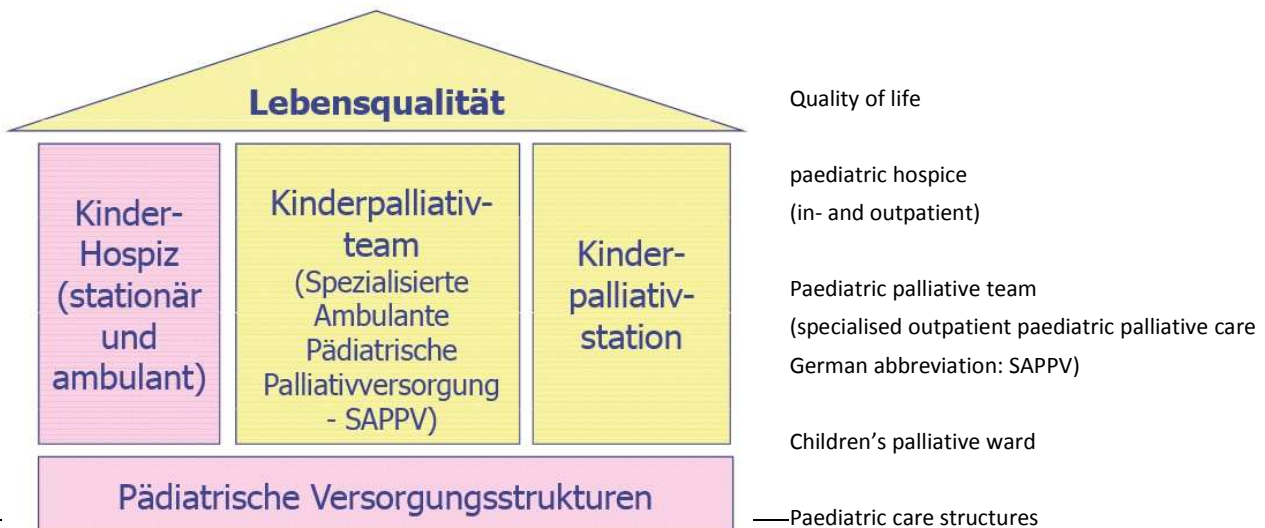
but: 4 pairs of parents felt themselves left alone during the last phase of life

- care exclusively via telephone
- Problem of palliative care in rural regions

Place of death in comparison (1 –16 years old)



Pillars of comprehensive palliative care of children in Bavaria





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Palliative care of children and adolescents throughout Bavaria locations:



Standorte:

München
Nürnberg/Erlangen
Augsburg/Neuburg
Regensburg
Amberg/Bayreuth
Würzburg

AG Kinderpalliativmedizin in Bayern im Auftrag des Bayerischen Ministeriums für Umwelt und Gesundheit

AG Paediatric palliative medicine in Bavaria commissioned by the Bavarian Ministry for health and the environment

“Yes, the children, even the very little ones, did not just die any kind of death: they gathered themselves together and died as that which they clearly were, and as that which they would have become.”

Rainer Maria Rilke, from „The Notebooks of Malte Laurids Brigge“

!Thanks!

To all children and their families

Director of Paediatric Clinic: Prof. Dr. D. Reinhardt; colleagues of HOME Project: Dr. Monika Grasser, Dr. Dorothe Carrle, Elisabeth Berger, Silke Schnüttgen, Christine Kyber, Anne Franke, Gertrud Krauss, René Vollenbroich; Pastoral care: Prof. Dr. Traugott Roser, Tanja Stiehl

Chair of Palliative Medicine: Prof. Dr. G.D. Borasio