2018

VIENNA, AUSTRIA

SUPPORTIVE CARE MAKES EXCELLENT CANCER CARE POSSIBLE

28-30 JUNE 2018

MASCC/ISOO

ANNUAL MEETING ON SUPPORTIVE CARE IN CANCER

MASCC Multinational Association of Supportive Care in Cancer

ISOO International Society of Oral Oncology

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#MASCC18


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Pognostication in pediatric oncology palliative care
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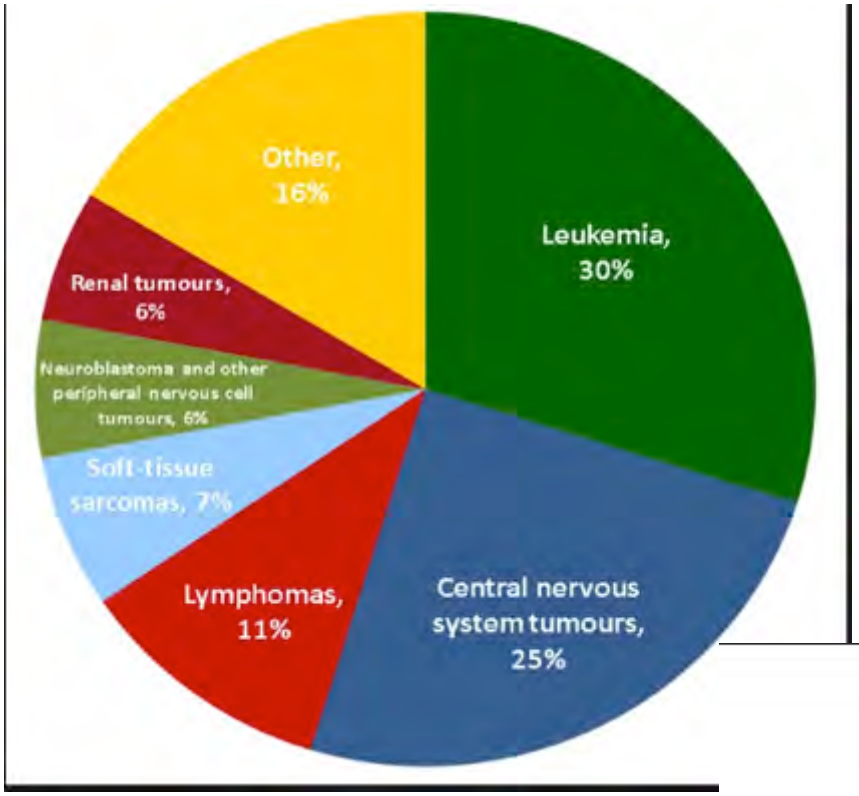

Childhood cancer
Reaches 80% survival
overall

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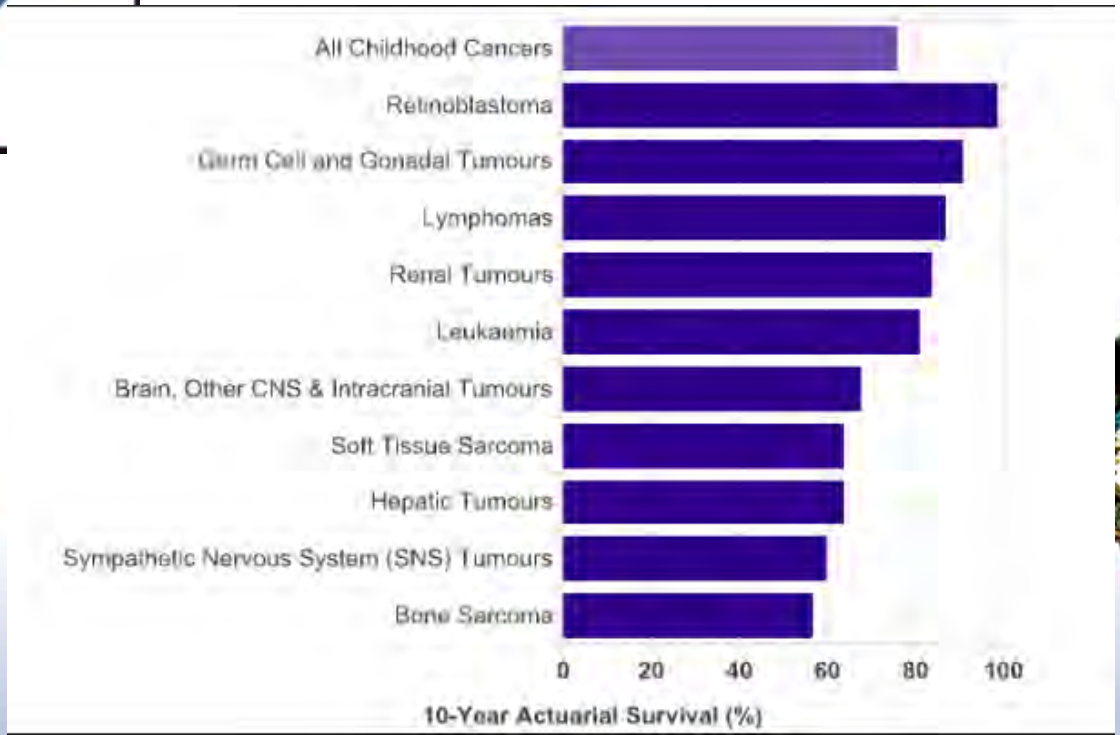

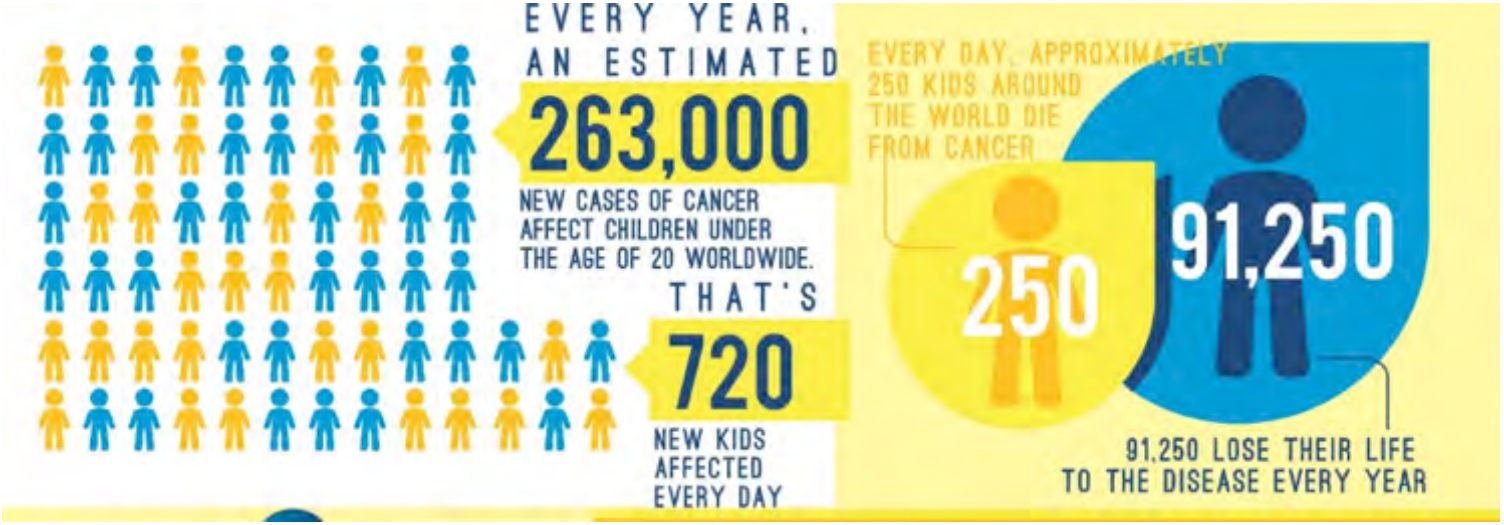

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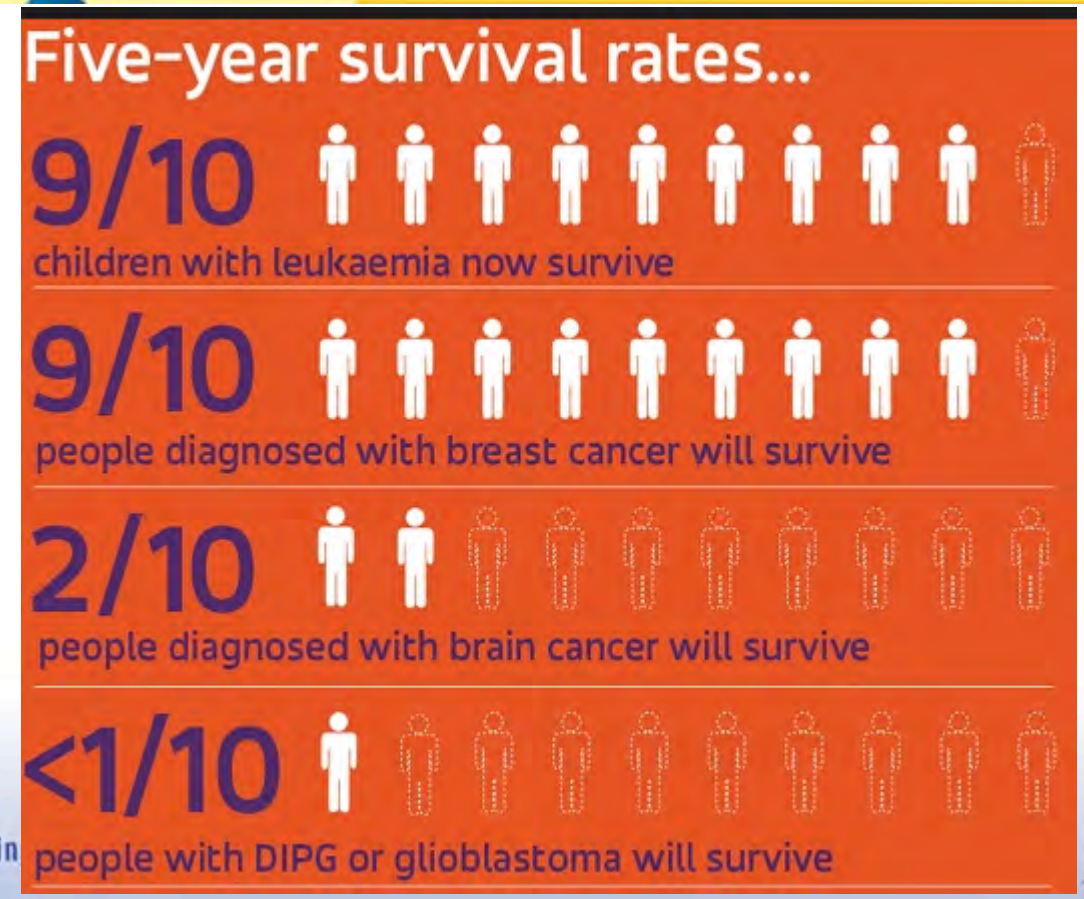

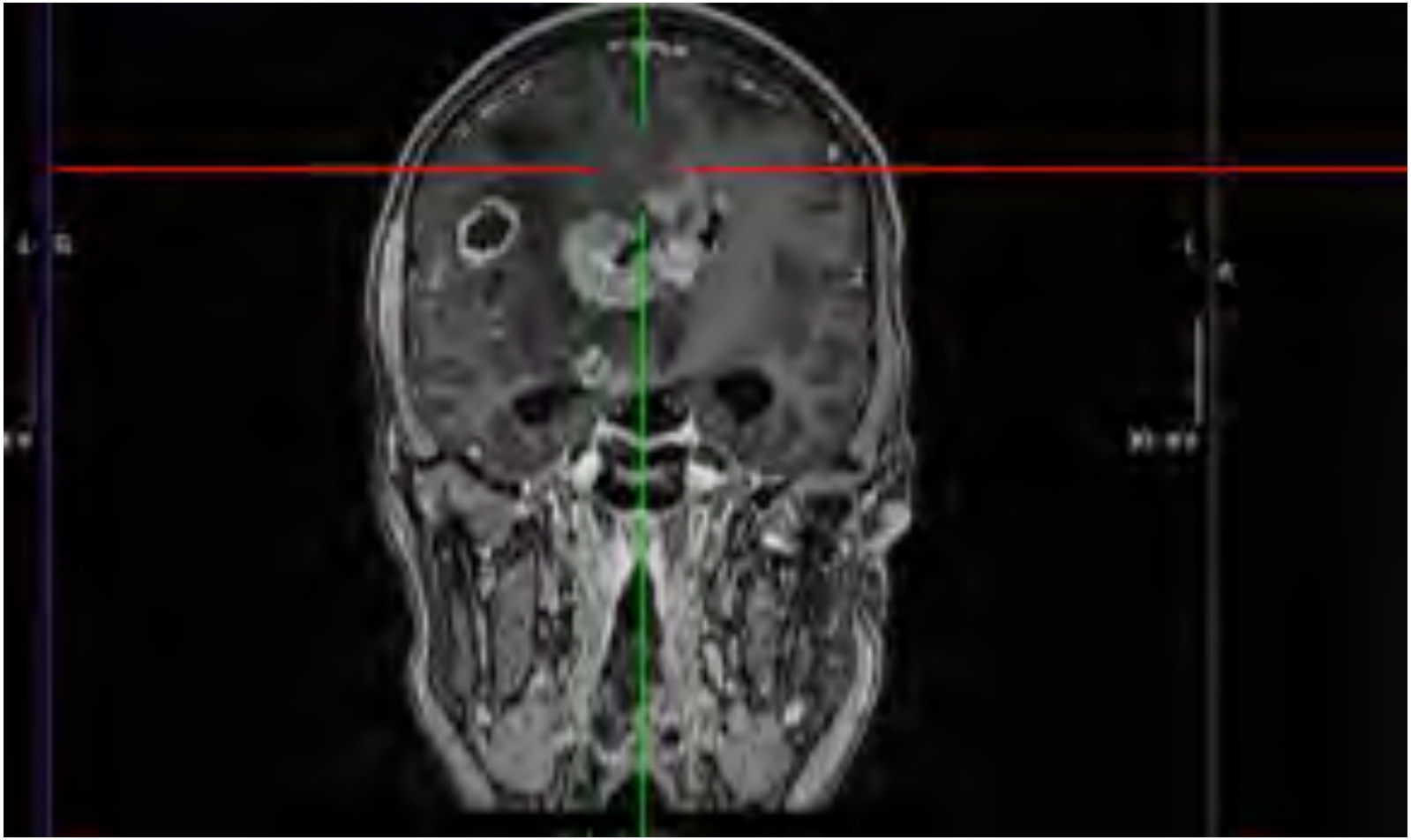

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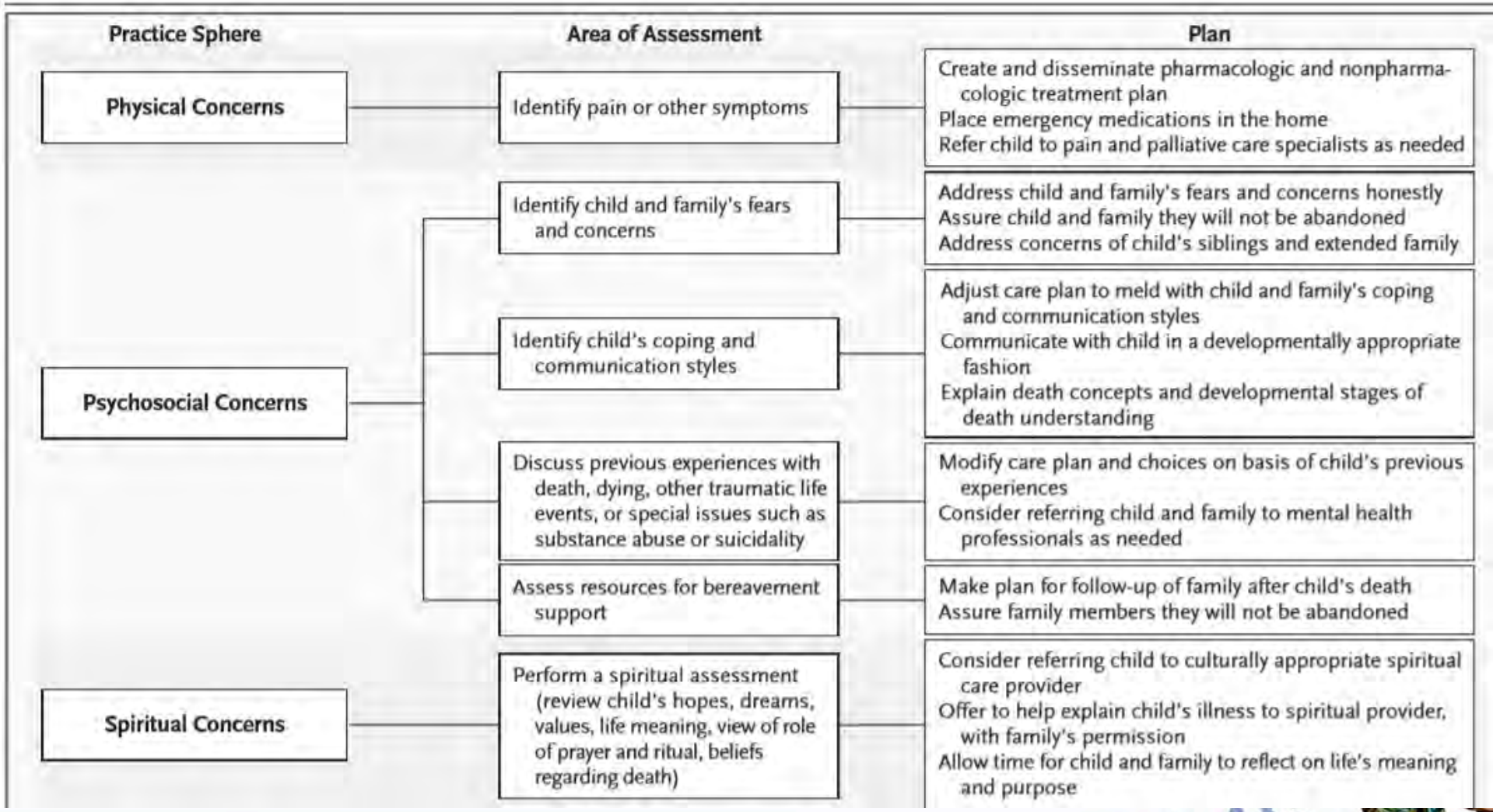
16 year old boy Glioblastoma Multiforme WHO IV

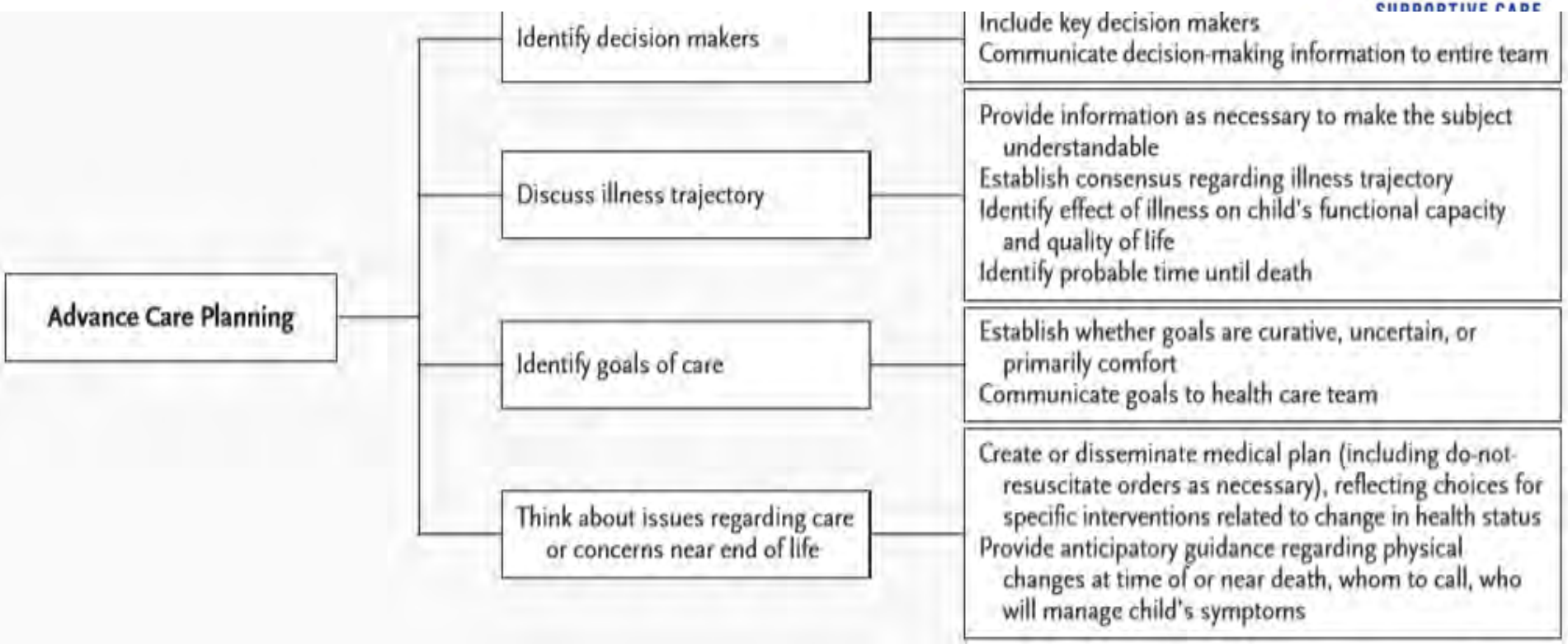
Treatment RT + temozolamide and maintenance Temozolamide x 6 months

9 month after diagnosis he progressed Reirradiation no effect,

Deterioration clinical condition- Palliative phase

How to Prognosticate


Practice Sphere
Area of Assessment
Plan
Physical Concerns
Identify pain or other symptoms
Create and disseminate pharmacologic and nonpharmacologic treatment plan
Place emergency medications in the home
Refer child to pain and palliative care specialists as needed
Psychosocial Concerns
Identify child and family's fears and concerns
Address child and family's fears and concerns honestly
Assure child and family they will not be abandoned
Address concerns of child's siblings and extended family
Identify child's coping and communication styles
Adjust care plan to meld with child and family's coping and communication styles
Communicate with child in a developmentally appropriate fashion
Explain death concepts and developmental stages of death understanding
Discuss previous experiences with death, dying, other traumatic life events, or special issues such as substance abuse or suicidality
Modify care plan and choices on basis of child's previous experiences
Consider referring child and family to mental health professionals as needed
Assess resources for bereavement support
Make plan for follow-up of family after child's death
Assure family members they will not be abandoned
Spiritual Concerns
Perform a spiritual assessment (review child's hopes, dreams, values, life meaning, view of role of prayer and ritual, beliefs regarding death)
Consider referring child to culturally appropriate spiritual care provider
Offer to help explain child's illness to spiritual provider, with family's permission
Allow time for child and family to reflect on life's meaning and purpose



Integrated Care Model

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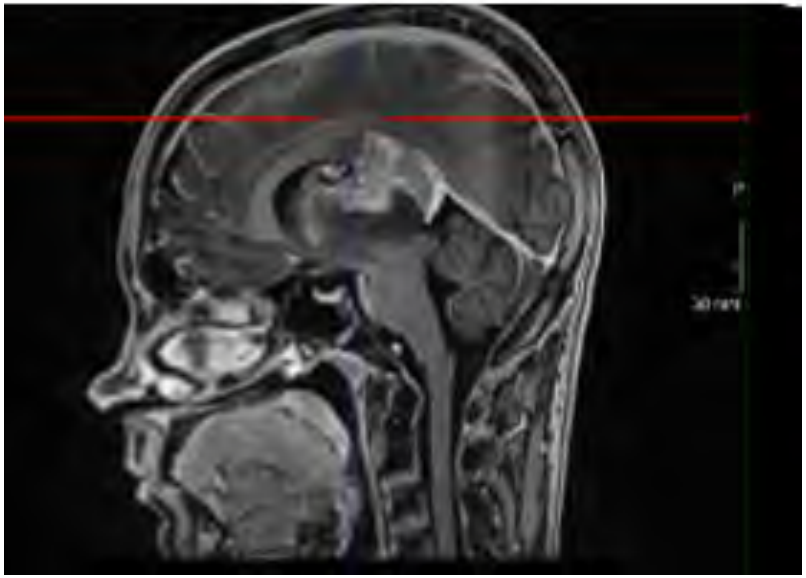

Aug 2017 primary diagnosis

Initial treatment RT and Temozolamide

April 2018 relapse

RT? Trial involvement
Palliative care

Neuro-Oncology Practice 2(2), 70–77, 2015
doi:10.1093/nop/npu038
Advance Access date 24 March 2015

Table 2. Patient characteristics and symptoms categorized per tumor type

	Medulloblastoma sPNET	Anaplastic Ependymoma	ATRT	DIPG	GBM	Other[a]	Total
Total	8	4	5	5	7	5	34
Characteristics at initial diagnosis							
Median age, y	7.2	6.6	6.5	6.9	9.0	6.6	6.4
Range age, y	2.2–17.1	1.9–15.9	0.5–16.9	4.7–11.4	4.6–17.2	0.4–15.6	0.4–17.2
Metastases at initial diagnosis, *n* (%)	2 (25%)	2 (50%)	2 (40%)	0	0	3 (60%)	9 (26%)
Initial resection, *n* (%)	8 (100%)	4 (100%)	4 (80%)	0	6 (86%)	3 (60%)	25 (74%)
Complete resection, *n* (%)	6 (75%)	0	0	0	0	1 (20%)	7 (21%)
Days from initial diagnosis to incurable disease[b]							
Median	695.5	401.5	246	0	93	272	168
Range	156–1008	86–2480	109–469	0-0	0–231	71–617	0–2480
Reason for start palliative phase[c]							
Incurable from diagnosis, *n* (%)	0	0	0	5 (100%)	3 (43%)	0	8 (24%)
Progression during treatment, *n* (%)	1 (12,5%)	2 (50%)	4 (80%)	0	4 (57%)	4 (80%)	15(44%)
Recurrence after CR, *n* (%)	7 (87,5%)	2 (50%)	1 (20%)	0	0	1 (20%)	11(32%)
Anticancer therapy in palliative phase[d]							
Chemotherapy, *n* (%)	6 (75%)	1 (25%)	0	2 (40%)	4 (57%)	5 (100%)	18 (53%)
Duration, d (range)	305 (5–350)	50 (no range)		107 (83–130)	55 (5–86)	54 (3–190)	54 (3–350)
Radiotherapy, *n* (%)	2 (25%)	0	0	4 (80%)	3 (43%)	1 (20%)	10 (29%)
Duration, d (range)	1 (no range)			17 (30–28)	30 (17–39)	6 (no range)	16 (1–39)
Surgery, *n* (%)	1 (12,5%)	0	0	0	1 (14%)	3 (60%)	5 (15%)
Duration of palliative phase in days[e]							
Median	261	52	50	116	82	56	80
Range	19–603	1–243	5–92	68–576	7–227	47–326	1–603
Days before death that last anticancer therapy was administered (curative or palliative)							
Median, *n*	78	66	96	48	26	16.5	43
Range, *n*	7–256	0–653	6–122	0–89	1–134	7–26	0–653

Neuro-Oncology Practice 2(2), 70–77, 2015
doi:10.1093/nop/npu038
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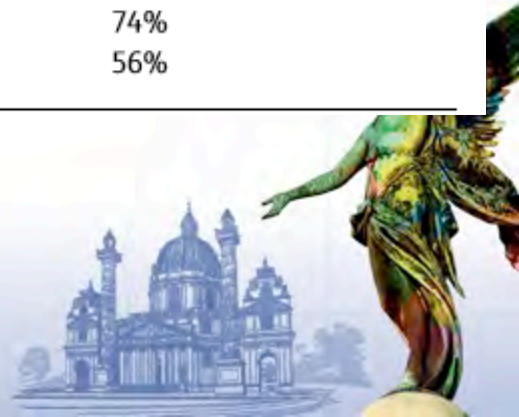
Table 1. Symptoms during palliative care in children with a brain tumor presented in the literature

	Hongo et al 2003[4]	Jalmsell et al 2006[6]	Goldman et al 2006[7]	Pritchard et al 2008[5]	Jagt et al 2015[8]
Patients with brain tumor (*n*)	7	157	59	18	34
Prospective/retrospective	Retrospective	Retrospective	Prospective	Retrospective	Retrospective
Presence of symptoms defined:	At any point during palliative phase	At any point during last month before death	At any point during palliative phase	At any point during palliative phase	On a weekly basis from start of palliative phase until death
Poor appetite	100%	53%	58%	17%	
Dyspnea	57%	29%	39%	22%	26%
Pain	71%	64%	81%	56%	91%
Fatigue	43%	83%	58%	11%	44%
Nausea/vomiting	57%	62%/52%	63%/64%	6%	53%
Constipation	71%	45%	58%		35%
Disturbed consciousness	100%				71%
Reduced mobility/paralysis		82%/55%	90%		74%
Seizures			39%		56%

All above symptoms were present in our patient



Neuro-Oncology Practice 2(2), 70–77, 2015
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Advance Access date 24 March 2015

Table 3. Occurrence of symptoms

	Medulloblastoma *n* (%)	Anaplastic Ependymoma *n* (%)	ATRT *n* (%)	DIPG *n* (%)	GBM *n* (%)	Other *n* (%)	Total *n* (%)
Pain	7 (87.5%)	3 (75%)	5 (100%)	5 (100%)	6 (86%)	5 (100%)	31 (91%)
Decreased mobility[a]	5 (62.5%)	4 (100%)	2 (40%)	5 (100%)	6 (86%)	3 (60%)	25 (74%)
Somnolence	4 (50%)	3 (75%)	3 (60%)	4 (80%)	5 (71%)	3 (60%)	24 (71%)
Change of cognition[b]	5 (62.5%)	2 (50%)	5 (100%)	2 (40%)	5 (71%)	5 (100%)	22 (65%)
Change of appearance[c]	4 (50%)	3 (75%)	3 (60%)	5 (100%)	3 (43%)	3 (60%)	21 (62%)
Seizures	5 (62.5%)	2 (50%)	2 (40%)	1 (20%)	7 (100%)	2 (40%)	19 (56%)
Sight/hearing disorders	6 (75%)	2 (50%)	1 (20%)	3 (60%)	3 (43%)	3 (60%)	18 (53%)
Vomiting	2 (25%)	2 (50%)	4 (80%)	2 (40%)	5 (71%)	3 (60%)	18 (53%)
Fatigue	5 (62.5%)	1 (25%)	2 (40%)	2 (40%)	2 (29%)	3 (60%)	15 (44%)
Speech disorders	2 (25%)	1 (25%)	2 (40%)	5 (100%)	1 (14%)	2 (40%)	13 (38%)
Constipation	3 (37,5%)	0	2 (40%)	2 (40%)	2 (29%)	3 (60%)	12 (35%)
Dyspnea	1 (12,5%)	1 (25%)	1 (20%)	2 (40%)	3 (43%)	1 (20%)	9 (26%)
Insomnia	3 (37,5%)	0	1 (20%)	3 (60%)	1 (14%)	1 (20%)	9 (26%)
Incontinence	3 (37,5%)	2 (50%)	1 (20%)	0	1 (14%)	1 (20%)	8 (24%)
Urinary retention	1 (12,5%)	1 (25%)	1 (20%)	2 (40%)	2 (29%)	1 (20%)	8 (24%)
Dysphagia	1 (12,5%)	1 (25%)	1 (20%)	2 (40%)	1 (14%)	1 (20%)	7 (21%)

(N Engl J Med 2000;342:326-33.)

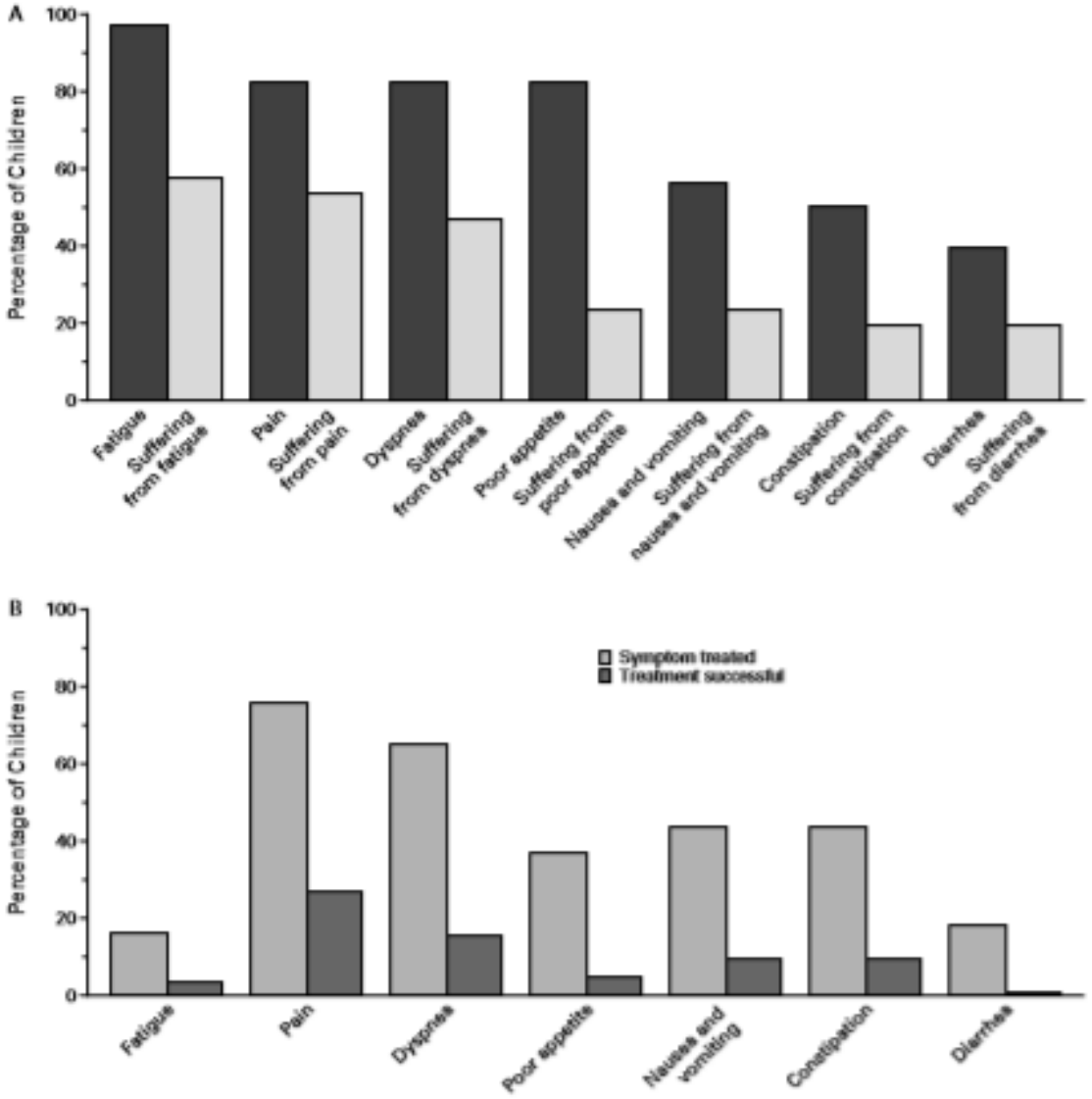


Figure 1. The Degree of Suffering from and the Success of Treatment of Specific Symptoms in the Last Month of Life.
Panel A shows the percentages of children who, according to parental report, had a specific symptom in the last month of life and who had "a great deal" or "a lot" of suffering as a result. Panel B shows the percentages of children who, according to parental report, were treated for a specific symptom in the last month of life, and in whom treatment was successful (rather than "somewhat successful" or "not successful").

Jagt- van Kampen et al.: The palliative phase of children with a brain tumor

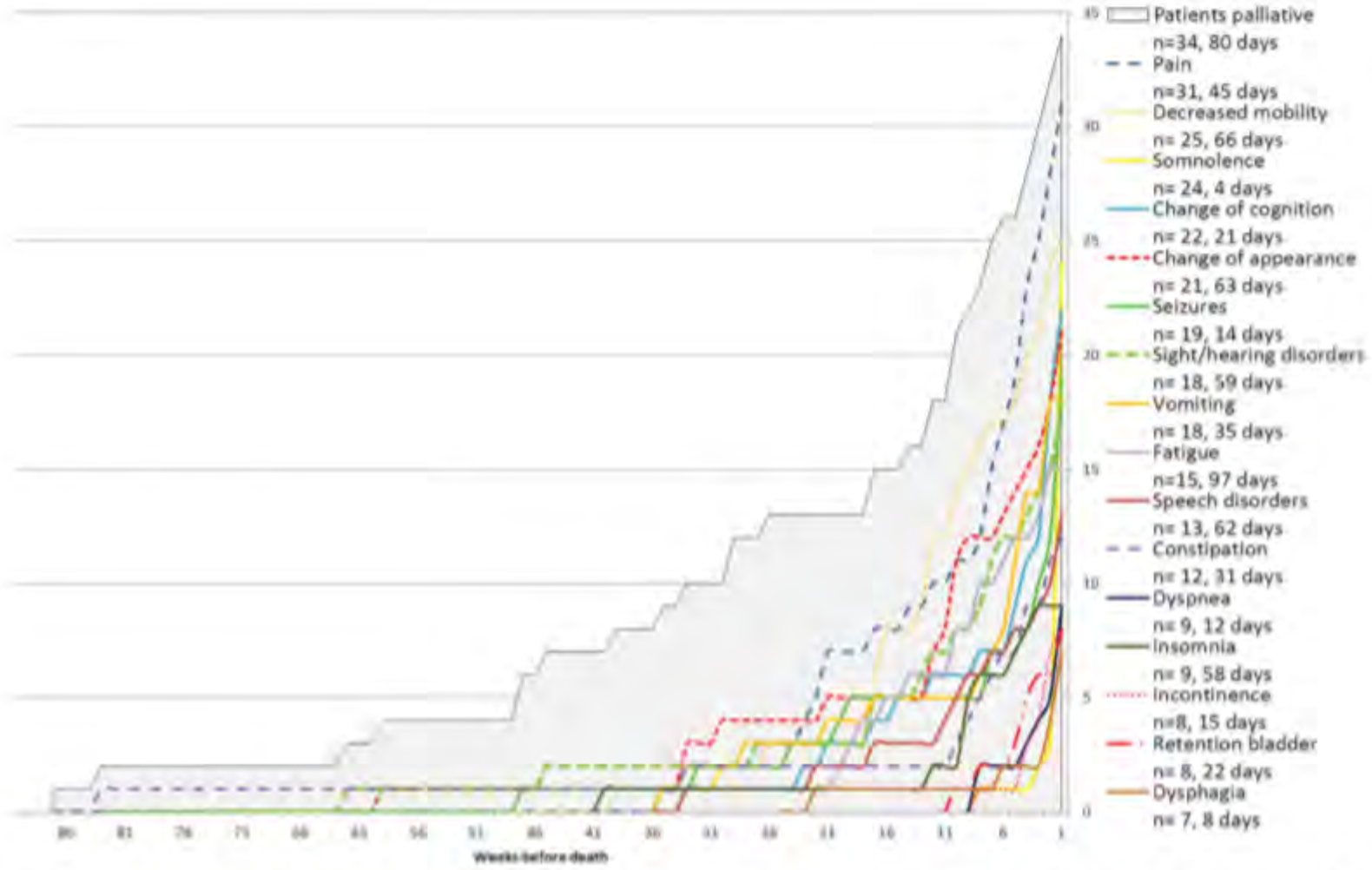


Figure 1. The lines provide the timing of occurrence and duration of symptoms. The horizontal axis gives the number of weeks before death for all patients. The gray area describes how many patients are in the palliative phase in each week. Each separate line depicts how many patients were recorded as having a specific symptom in each week. At right, symptoms are ranked from highest occurrence to lowest. For each symptom, the number of patients with the symptom is given, as is the median number of days the symptom occurred before death.

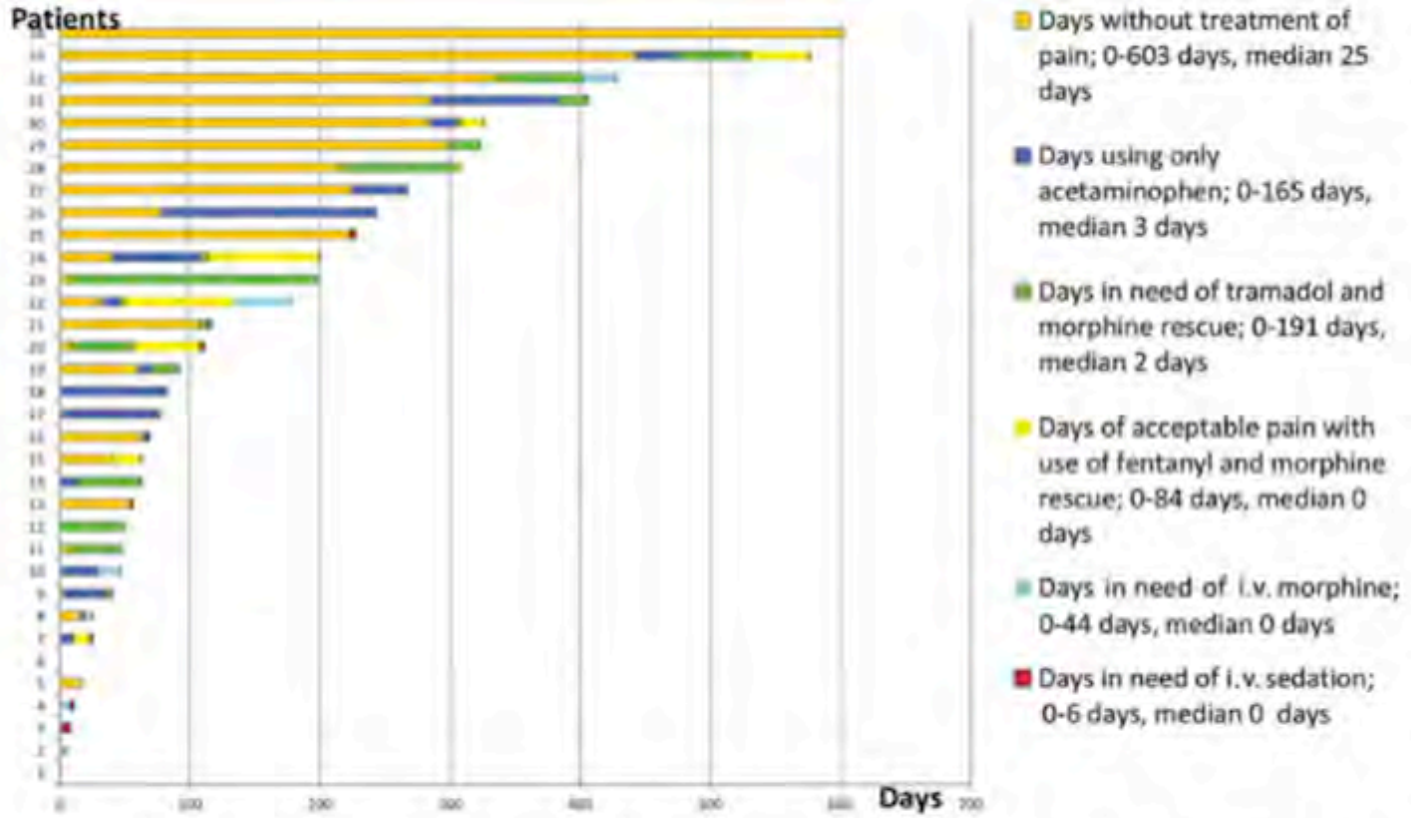


Figure 2. Pain medication during the palliative phase. This figure presents a timeline, in days, for each patient. The length of each timeline indicates the duration of the palliative period for the specific patient, presented in days. The colors indicate the duration that pain medication was used. Each medication was added to previous medications.

Knops et al. BMC Palliative Care (2015) 14:57
DOI 10.1186/s12904-015-0054-7

BMC Palliative Care

RESEARCH ARTICLE Open Access

Paediatric palliative care: recommendations for treatment of symptoms in the Netherlands

Rutger R. G. Knops[1*], Leontien C. M. Kremer[1], A. A. Eduard Verhagen[2] and on behalf of the Dutch Paediatric Palliative Care Guideline Group for Symptoms

Abstract

Background: Children dying of a life threatening disease suffer a great deal at the end of life. Symptom control is often unsatisfactory, partly because many caregivers are simply not familiar with paediatric palliative care. To ensure that a child with a life-threatening condition receives high quality palliative care, clinical practice guidelines are needed. The aim of this study is to improve palliative care for children by making high quality care recommendations to recognize and relieve symptoms in paediatric palliative care.

Methods: An extensive search was performed for guidelines and systematic reviews on paediatric palliative care up to year 2011. An expert panel combined the evidence with consensus to form recommendations on the treatment of symptoms in paediatric palliative care.

Results: We appraised 21 guidelines and identified 693 potentially eligible articles of which four met our inclusion criteria. None gave recommendations on the treatment of symptoms in paediatric palliative care. Two textbooks and an adult palliative care website were eventually our main sources of evidence.

Conclusion: Hardly any evidence is available for the treatment of symptoms in paediatric palliative care. By combining evidence for adult palliative care and the sparse evidence for paediatric palliative care with expert opinion we defined a unique set of high quality care recommendations to relieve symptoms and lessen the suffering of children in palliative care. These results are an important tool to educate caregivers on how to relieve symptoms in children in paediatric palliative care.

Table 3 Recommendations for treatment of symptoms in paediatric palliative care

- Anxiety and depression	
Do	• Consult a psychologist, paediatric psychiatrist, if necessary a physician for people with intellectual disabilities or someone of a similar discipline.
	• Decide in deliberation with the parents the mode of treatment for the anxiety and/or depression of the child.
	• Involve a spiritual caregiver (possibly of the family's own conviction) to help with existential philosophical questions.
	• Offer relaxation and distraction techniques in case of anxiety.
Consider	• Consider selective serotonin reuptake inhibitors (SSRI's) in case of anxiety, whether or not accompanied by depression.
	• Consider methylphenidate in case of depression.
	• Consider the help of experts for self-hypnosis.

Table 1 Level of evidence for interventions

Level of evidence	Evidence is based on:
Level 1	Systematic review or at least two randomized clinical trials of good quality
Level 2	One randomized clinical trial or at least two case–control studies
Level 3	One case–control study or one cohort study
Level 4	Textbook or expert opinion

Appendix 3 Evidence table for the treatment of symptoms

Treatment	Level of evidence for children	Level of evidence for adults	Effectiveness
Anxiety and depression			
General interventions for anxiety (cognitive and behavioural interventions)	Level 3 [1-4]	Level 1 [5,6]	Effective (adult) Possibly effective (child)*
Benzodiazepines for anxiety	Level 4 [7,8]	Level 3 [9-11]	Possibly effective (adult) Possibly effective (child)
SSRI's for anxiety	Level 4 [12]	Level 1 [13]	Effective (adult) Possibly effective (child)
SSRI's for anxiety and depression for children with cancer	Level 4 [14-16]	Level 1 [13]	Effective (adult) Possibly effective (child)
General interventions for depression (cognitive and behavioural interventions)	Level 1 [7]	Level 1 [17-20]	Effective (adult) Effective (child)
SSRI's for depression	Level 3 [12,21,22]	Level 1 [18-20,23,24]	Effective (adult) Possibly effective (child)
Tricyclic antidepressants	Controversy [25,26]	Level 1 [18-20,24]	Effective (adult) Controversy (child)

- *Pain*

Do • Treat pain according to a set (time) scheme, use the most suitable way and adjust to the needs of the child.

Consider • Consider melatonin for headaches and sleeping disorders.

• Consider complementary therapies.

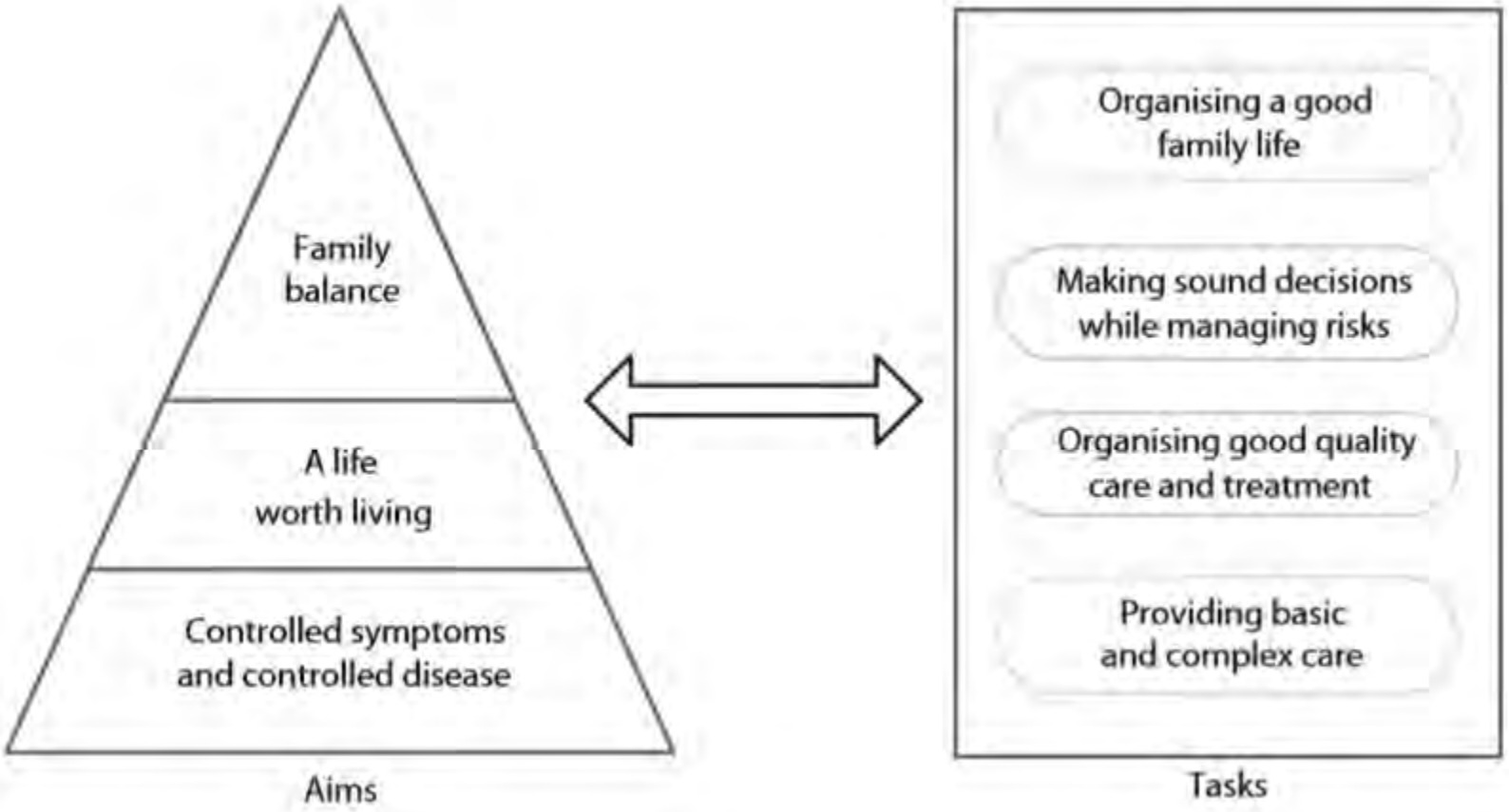
Treatment	Level of evidence for children	Level of evidence for adults	Effectiveness
Pain			
Integrative therapies	Level 2 [183,184]		Possibly effective*
Psychological therapy	Level 1 [185]		Effective
Acetaminophen	n.a. [186]		Effective
NSAID	n.a. [186]		Effective
Tramadol	n.a. [186]		Possibly effective
Codeine	n.a. [186]		Controversy
Morphine	n.a. [186]	Level 3 [187]	Effective
Oxycodone	n.a. [186]		Possibly effective
Buprenorphine	n.a. [186]		Possibly effective
Corticosteroids	n.a. [186]		Possibly effective
Amitriptyline		Level 1 [188,189]	Effective (adult)
Gabapentin Pregalabine		Level 1 [189-191]	Effective (adult)
Phenytoin Carbamazepine Valproate acid		Controversy [189]	Controversy
Opioids		Level 1 [189,192]	Effective

Eur J Pediatr
DOI 10.1007/s00431-016-2842-3

ORIGINAL ARTICLE

Aims and tasks in parental caregiving for children receiving palliative care at home: a qualitative study

Lisa M. Verberne[1] · Marijke C. Kars[1] · Antoinette Y. N. Schouten-van Meeteren[2] · Diederik K. Bosman[3] · Derk A. Colenbrander[3] · Martha A. Grootenhuis[4,5] · Johannes J. M. van Delden[1]



Conclusion on how to offer best palliative care for LLC

- Adequate communicative skills
- Guidelines as tool to educate care givers
- Prediction of symptoms based on research
- And a palliative care team to support child parents and siblings.

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And our patient????

He chose to stay in the hospital and spend his last days with his family around him

He was prepared as to what was going to happen and was not anxious…….

Thank You For Listening

Any Questions?

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