Due parole per fare silenzio

La sedazione palliativa

Monfalcone, 10 novembre 2016

Cure Palliative Pediatriche

Attiva presa in carico globale del corpo, della mente, e dello spirito del bambino e della sua famiglia.. nell'ottica della qualità della vita (OMS 1998) - interdisciplinarietà

Non sono le cure dei morenti

Iniziano al momento della diagnosi e continuano indipendentemente dal fatto che continui o meno la terapia curativa

Risposta residenziale

Quando?

Eleggibilità

NON PUO’

….. basarsi sul parametro dell’aspettativa di vita, poiché tale tempo è quanto mai variabile (da giorni ad anni), né su quello della diagnosi limitata e definita ad un gruppo di patologie. Nemmeno un decorso con un continuo e prevedibile decadimento delle funzioni e delle condizioni cliniche è un elemento assoluto di selezione, perché in età pediatrica le situazioni cliniche che richiedono cure palliative, anche specialistiche, presentano un andamento alterno e lunghi periodi di stato.

•Bambini con patologie per le quali esiste un trattamento specifico, ma che può fallire in una quota di essi. (patologie *life-threatening*) Le cure palliative intervengono quando il trattamento volto alla guarigione fallisce (Es. neoplasie, insufficienza d'organo irreversibile)

•Bambini con patologie in cui la morte precoce è inevitabile, ma cure appropriate possono prolungare ed assicurare una buona qualità di vita (Patologie *life-limiting*. Es. fibrosi cistica)

•Bambini con patologie progressive, per le quali il trattamento è quasi esclusivamente palliativo e può essere esteso anche per molti anni (Patologie life-limiting. Es. malattie degenerative neurologiche e metaboliche, patologie cromosomiche e geniche)

•Bambini con patologie irreversibili ma non progressive, che causano disabilità severa, e morte prematura (Es. paralisi cerebrale severa, disabilità per sequele di danni cerebrali e/o midollari).

The *Association for Children with Life-limiting and Terminal Illness* e il *Royal College of Paediatrics and Child Health 2004*

Quando?

Quali Bambini ?

Pazienti oncologici
Pazienti neurologici
Pazienti muscolari
Pazienti metabolici
Pazienti cardiopatici
Patologia cromosomica
Malformazioni…

E' esaustiva ?

Quando nella storia di malattia?

IMPaCCT: Standards for Paediatric- Palliative Care in Europe. EUROPEAN JOURNAL OF PALLIATIVE CARE, 2007; 14(3)

Eleggibilità

E’ facile definire l’inguaribilità?

L'inguaribilità nel bambino oncologico

In teoria. Una patologia oncologica viene dichiarata inguaribile quando si è di fronte a più recidive di malattia resistenti a terapie di linee successive alla prima (incluso il Trapianto di Midollo Osseo e/o di cellule staminali emopoietiche) e per le quali da un punto di vista scientifico, non si intravede più possibilità di guarigione.

In pratica. E' univoco significato reale di "più recidive di malattia resistenti a terapie" e significato di " da un punto di vista scientifico, non si intravede più possibilità di guarigione" ?

Continua revisione del concetto di inguaribilità
Drammaticità della situazione, le richieste di guarigione della famiglia, la continua messa a disposizione di strategie alternative/sperimentazioni

Risultato

La definizione di inguaribilità di un bambino con malattia oncologica da parte dell'equipe di cura può non essere condivisa in modo univoco dalla comunità scientifica e/o all'interno della stessa equipe curante

Problema delle CPP = Cure della terminalità

Considerazioni utili

- la diagnosi di inguaribilità, in alcune tipologie di tumori (es. cerebrali e altri tumori solidi) è possibile anche precocemente sulla base della sede del tumore, della tipologia istologica e della storia di malattia *(Tumore cerebrale)*

- è importante porsi il problema di una eventuale diagnosi di inguaribilità durante le diverse fasi della storia della malattia per il passaggio dalle CPP generali a quelle specialistiche *(Malattia onco-ematologica).*

Situazione da proporre alle CPP specialistiche

ALLA DIAGNOSI	DURANTE LA MALATTIA
Diffuso glioma intrinseco del tronco	Malattia resistente al trattamento
Neuroblastoma IV stadio	Malattia in progressione (es. nuove metastasi)
Tumore solido metastatico	Malattia recidivata dopo la remissione
Qualsiasi altro tipo di tumore con una previsione di EFS<40% con le attuali terapie	Malattia resistente o recidivata dopo il trapianto di cellule staminali ematopoietiche
Qualsiasi altra malattia in cui il trapianto di cellule staminali ematopoietiche sia parte della terapia di prima linea	Comparsa di complicazioni a rischio di vita (es. insufficienza d'organo, intubazione prolungata)
	Sviluppo di una nuova e significativa tossicità correlata al trattamento e/o stress psicosociale

L'inguaribilità nel bambino non oncologico

Malattie *life-limiting* e *life-threatening* non concologiche colpiscono più del 75 dei bambini eleggibili alle CPP

- Bambini con malattia **"*life-limiting*"**

la diagnosi d'inguaribilità è insita nella diagnosi della patologia di base, indipendentemente dall'età del bambino, dal luogo in cui vive e dalle risorse a disposizione.

- Bambini con malattia **"life threatining"**

patologie per le quali il trattamento curativo è possibile ma può fallire, per esempio nel caso del bambino con insufficienza d'organo in attesa di trapianto.

L'inguaribilità nel bambino non oncologico

Bambini con malattia ***"life-limiting"***

•La diagnosi di inguaribilità è fatta sulla base della indisponibilità attuale di terapia in grado di portare il bambino alla guarigione

•Sono frequentemente malattie genetiche, cromosomiche rare, che per lo più si evidenziano in fasi molto precoci della vita ed anche prima della nascita.

•È certamente la categoria di bambini per cui è più semplice definire l'inguaribilità e, di seguito, avviare un percorso di valutazione di eleggibilità alle CPP specialistiche sulla base dei bisogni

Bambini con malattia **“*life threatining*”**

In quanto patologie *life-threatening* è importante ricordare:

•di considerare la diagnosi di "probabile inguaribilità" in caso di scarsa risposta alla terapia, riacutizzazioni o insorgenza di complicazioni che portino il paziente a rischio di morte imminente (come emerge sulla base dell’esperienza clinica)

•di considerare la diagnosi di "probabile inguaribilità", in caso di necessità prolungata di presidi per il sostegno delle funzioni vitali, senza i quali il bambino non può vivere. (es. la ventilazione meccanica, la dialisi, il cuore meccanico)

Bambini con **malattia “senza diagnosi”**

è importante considerare la diagnosi di "probabile inguaribilità" in caso di

✓sintomi d'insufficienza d'organo che non lasciano spazio ad un ragionevole recupero o miglioramento,
✓sintomi severi e ingravescenti spesso non rispondenti alle terapie, riacutizzazioni e complicazioni frequenti che portano il paziente a rischio di morte,
✓interessamento multiorgano
✓decadimento "globale" della salute del piccolo paziente.

Situazione da proporre alle CPP specialistiche

ALLA DIAGNOSI	DURANTE LA MALATTIA
Malattia inguaribile con prognosi infausta, a rischio di morte precoce	Malattia con sintomi ingravescenti che non rispondono alle terapie.
	Malattia con diagnosi di inguaribilità in cui si rileva un aumento dei bisogni clinici/psicologici/sociali/etici
	Accompagnamento alla terminalità e alla gestione del lutto.

Tutti i bambini inguaribili sono eleggibili alle CPP?

Quando nella storia di malattia?

Eleggibilità

- Inguaribilità
- Complessità assistenziale

Quanto grandi sono i bisogni ?

Paediatric Palliative Screening Scale (PaPaS Scale)

ACCAPED

Quando un bambino diventa terminale?

CPP Fine vita - Terminalità

Diagnosi

Previsione di guarigione

- Diagnosi nota (il valore della %)
- Diagnosi NON nota

Nuove terapie/presidi

CPP fine vita -Terminalità

Madre?

Padre?

Altri?

TERMINALE PER CHI ?

CPP

Fine Vita -Terminalità

Team Sanitario

Scarsa formazione

Difficoltà di mantenere i ruoli

Impatto emotivo

Non univocità

European Journal of Cancer (2015) 51, 1618–1629

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ScienceDirect

journal homepage: www.ejcancer.com

Survival prediction for advanced cancer patients in the real world: A comparison of the Palliative Prognostic Score, Delirium-Palliative Prognostic Score, Palliative Prognostic Index and modified Prognosis in Palliative Care Study predictor model

Mika Baba [a,*], Isseki Maeda [b], Tatsuya Morita [c], Satoshi Inoue [d], Masayuki Ikenaga [e], Yoshihisa Matsumoto [f], Ryuichi Sekine [g], Takashi Yamaguchi [h], Takeshi Hirohashi [i], Tsukasa Tajima [j], Ryohei Tatara [k], Hiroaki Watanabe [l], Hiroyuki Otani [m,n], Chizuko Takigawa [o], Yoshinobu Matsuda [p], Hiroka Nagaoka [q], Masanori Mori [r], Yo Tei [d], Shuji Hiramoto [s], Akihiko Suga [t], Hiroya Kinoshita [f]

[a] Palliative Care Division, Saito Yukoukai Hospital, 7-2-18 Saito asagi, Ibaraki, Osaka 567-0085, Japan
[b] Department of Palliative Medicine, Graduate School of Medicine, Osaka University, 2-2 Yamadaoka, Suita, Osaka 565-0871, Japan
[c] Palliative and Supportive Care Division, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Kita-ku, Hamamatsu City, Shizuoka 433-8558, Japan
[d] Seirei Hospice, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Kita-ku, Hamamatsu City, Shizuoka 433-8558, Japan
[e] Children's Hospice Hospital, Yodogawa Christian Hospital, 6-9-3 Higashinakajima, Higashiyodogawa-ku, Osaka City 533-0033, Japan
[f] Department of Palliative Medicine, National Cancer Center Hospital East, 6-5-1 Kashiwanoha, Kashiwa, Chiba 277-8577, Japan
[g] Department of Pain and Palliative Care, Kameda Medical Center, Higashi-Cho 929, Kamogawa City, Chiba 296-8602, Japan
[h] Department of Palliative Medicine, Kobe University Graduate School of Medicine, 7-5-1 Kusunokicho, Chuo-ku, Kobe, Hyogo 650-0017, Japan
[i] Department of Palliative Care, Mitui Memorial Hospital, 1 Kandaizumicho, Chiyoda-ku, Tokyo 101-8643, Japan
[j] Department of Palliative Medicine, Tohoku University Hospital, 1-1 Seiryo-machi, Aobaku, Sendai 980-8574, Japan
[k] Osaka City General Hospital, Department of Palliative Medicine, 2-13-22 Miyakojima-hondori, Miyakojima-ku, Osaka 534-0021, Japan
[l] Komaki City Hospital, 1-20 Johushi, Komaki-city, Aichi 485-8520, Japan
[m] Department of Palliative Care Team, National Kyushu Cancer Center, 3-1-1 Notame, Minami-ku, Fukuoka 811-1395, Japan
[n] Department of Palliative and Supportive Care, National Kyushu Cancer Center, 3-1-1 Notame, Minami-ku, Fukuoka 811-1395, Japan
[o] Department of Palliative Care, KKR Sapporo Medical Center, Hiragishi 1-6, Toyohira-ku, Sapporo 062-0931, Japan
[p] Department of Psychosomatic Medicine, National Hospital Organization Kinki-Chuo Chest Medical Center, Sakai, Osaka 591-8555, Japan

* Corresponding author: Tel.: +81 72 641 6898; fax: +81 72 641 6097.
E-mail addresses: baba@saito-yukoukai-hp.jp (M. Baba), maeda@pm.med.osaka-u.ac.jp (I. Maeda), tmorita@sis.seirei.or.jp (T. Morita), inosa@sis.seirei.or.jp (S. Inoue), a190185@ych.or.jp (M. Ikenaga), yomatsu@east.ncc.go.jp (Y. Matsumoto), sekiner@kameda.jp (R. Sekine), ikagoro@pop06.odn.ne.jp (T. Yamaguchi), hirohashi.med@gmail.com (T. Hirohashi), ttajima@med.tohoku.ac.jp (T. Tajima), r-tatara@hotmail.co.jp (R. Tatara), hi.watanabe@komakihp.gr.jp (H. Watanabe), cas60020@pop21.odn.ne.jp (H. Otani), takki236@gmail.com (C. Takigawa), takki236@gmail.com (Y. Takigawa), takki236@gmail.com (Y. Takigawa), takki236@gmail.com (Y. Takigawa), takki236@gmail.com (Y. Takigawa), ymatsuda@kch.hosp.go.jp (Y. Matsuda), nagaoka3taro@gmail.com (H. Nagaoka), Masanori.Mori@sis.seirei.or.jp (M. Mori), y-jeong680909@ktb.biglobe.ne.jp (Y. Tei), otomarilrx.8@gmail.com (S. Hiramoto), otomarilrx.8@gmail.com (A. Hiramoto), akihikosuga@gmail.com (A. Suga), hikinosh@east.ncc.go.jp (H. Kinoshita).

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Quando?

Aggravamento della situazione clinica che risulta ragionevole pensare ad una morte imminente

Sintomi respiratori – Sintomi neurologici – Sintomi cardiocircolatori – Cachessia estrema

TEMPO

Evoluzione in acuto

Inalazione
Emorragia incontenibile
Aritmia cardiaca

Cure Palliative Pediatriche del fine vita

Cambiano i bisogni
Cambiano le priorità
Cambiano le relazioni

Comunicazione – Organizzazione - Deresponsabilizzazione

bisogni

La Piramide dei bisogni di Maslow

Bambino
Famiglia
Equipe

BISOGNI FISICI e ASSISTENZIALI

sintomi

BAMBINO ONCOLOGICO

- DOLORE
- ANORESSIA
- STIPSI
- NUTRIZIONE
- DISPNEA
- TOSSE
- EMERGENZE
- INSONNIA
- CACHESSIA

BISOGNI FISICI e ASSISTENZIALI
sintomi

BAMBINO NON ONCOLOGICO

- DISPNEA
- ANORESSIA
- PROBLEMI DI ALIMENTAZIONE
- NUTRIZIONE
- TOSSE
- SINTOMI NEUROLOGICI
- INSUFFICIENZA CARDIACA
- INSUFFICIENZA RENALE
- DOLORE
- INFEZIONE
- …

Best practice a livello clinico

Priorità d'intervento e di obiettivi sulla base del Percepito del paziente

Utilizzo di strategie farmacologiche e non

Attenzione agli effetti collaterali che vanno preventivamente trattati

Utilizzo di strumenti / presidi il meno invasivi possibile

Stop alle indagini/esami diagnostici che non prevedono soluzioni nell'ottica della qualità di vita del paziente

Decidere di non trattare

Monitoraggio della sedazione

Grado di sedazione: scala di Rudkin

1	Paziente sveglio e orientato
2	Sonnolente ma risvegliabile
3	Occhi chiusi ma risvegliabile alla chiamata
4	Occhi chiusi ma risvegliabile a stimolo tattile (non doloroso)
5	Occhi chiusi non rispondente ad uno stimolo tattile

Amore (espressioni d’affetto)

Comprensione (spiegazione, discussione)

Accettazione (a prescindere…)

Sicurezza - Appartenenza

Autostima (coinvolgimento…)

Fiducia (comunicazione onesta)


RIFERIMENTO CLINICO
SOSTEGNO PSICOLOGICO
SOSTITUZIONE
EDUCAZIONE
DERESPONSABILIZZAZIONE
FORMAZIONE
Condivisione


SOSTEGNO
FORMAZIONE
SUPERVISIONE
SUPPORTO
RUOLO
RISORSE

Importanza dell’ H24 e della multidisciplinarietà
Importanza dell’organizzazione
Importanza dell’assessment
Importanza della presenza
Importanza della NON delega

Sospensione del sostegno di presidi salvavita

Limitazione della Nutrizione

Sedazione terminale

Definizione

A Review of Palliative Sedation

Barton Bobb, MSN, FNP-BC, ACHPN

KEYWORDS

- Palliative sedation • End of life • Refractory symptoms • Midazolam
- Proportionate sedation

KEY POINTS

- Palliative sedation is a procedure used to treat refractory symptoms at end of life.
- Dyspnea and delirium are the most common physical symptoms addressed with palliative sedation, followed by pain and vomiting.
- The goal of palliative sedation is to alleviate intractable symptoms, but never to hasten the dying process, and it has not been found to do so.
- The process of palliative sedation continues to be surrounded by potential ethical concerns that are best discussed with patient and family before initiation.

INTRODUCTION

In spite of aggressive palliative measures, symptom management can sometimes become challenging at end of life. For these instances in which symptoms become refractory to standard treatment measures, the option of palliative sedation may be considered. The phrase terminal sedation was previously used, but was discontinued because the term implied that the goal was to shorten life.[1] The goal of palliative sedation is to relieve pain and suffering, never to shorten life. Systematic reviews of research involving the use of palliative sedation indicate that this intervention does not shorten patients' survival.[2,3] Two of the most common physical symptoms treated with palliative sedation are dyspnea and delirium.[2,4] Using palliative sedation to manage refractory nonphysical symptoms such as existential distress is less common and a more controversial practice that continues to be a topic of debate.[5–7]

CASE STUDY

M.B. is a 48-year-old man with advanced non–small cell lung carcinoma. He has been administered 3 lines of chemotherapy, multiple lung resections, and extensive

Disclosures: The author has no financial disclosures or conflicts of interest.
Thomas Palliative Care Services, Massey Cancer Center, Virginia Commonwealth University Health System, 1300 East Marshall Street, Richmond, VA 23298, USA
E-mail address: barton.bobb@vcuhealth.org

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nursing.theclinics.com

Sedazione palliativa

Riduzione intenzionale della vigilanza con
mezzi farmacologici, fino alla perdita di coscienza, allo scopo di ridurre
o abolire la percezione di un sintomo, altrimenti intollerabile per il
paziente, nonostante siano stati messi in opera i mezzi più adeguati per
il controllo del sintomo, che risulta, quindi, refrattario

Raccomandazioni della SICP - 2007

Sintomo refrattario

Il sintomo refrattario è un sintomo che non è controllato in modo adeguato, malgrado sforzi tesi a identificare un trattamento che sia tollerabile, efficace, praticato da un esperto e che non comprometta lo stato di coscienza

Bambini con malattia oncologica

Bambini con malattia NON oncologica

Problemi diversi – Situazioni diverse

Pediatr Blood Cancer 2014;61:2004–2011

End-of-Life Care in Pediatric Neuro-Oncology

Stefano Gabriele Vallero, MD,[1]* Stefano Lijoi, MD,[1] Daniele Bertin, MD, PhD,[1] Laura Stefania Pittana, MD,[1] Simona Bellini, Msc(Psy),[2] Francesca Rossi, DPT,[3] Paola Peretta, MD,[4] Maria Eleonora Basso, MD, PhD,[1] and Franca Fagioli, MD[1]

Background. The management of children with cancer during the end-of-life (EOL) period is often difficult and requires skilled medical professionals. Patients with tumors of the central nervous system (CNS) with relapse or disease progression might have additional needs because of the presence of unique issues, such as neurological impairment and altered consciousness. Very few reports specifically concerning the EOL period in pediatric neuro-oncology are available. ***Procedure.*** Among all patients followed at our center during the EOL, we retrospectively analyzed data from 39 children and adolescents with brain tumors, in order to point out on their peculiar needs. ***Results.*** Patients were followed-up for a median time of 20.1 months. Eighty-two percent were receiving only palliative therapy before death. Almost half the patients (44%) died at home, while 56% died in a hospital. Palliative sedation with midazolam was performed in 58% of cases; morphine was administered in 51.6% of cases. No patient had uncontrolled pain. ***Conclusions.*** The EOL in children with advanced CNS cancer is a period of active medical care. Patients may develop complex neurological symptoms and often require long hospitalization. We organized a network-based collaboration among the reference pediatric oncology center, other pediatric hospitals and domiciliary care personnel, with the aim to ameliorate the quality of care during the EOL period. In our cohort, palliative sedation was widely used while no patients died with uncontrolled pain. A precise process of data collection and a better sharing of knowledge are necessary in order to improve the management of such patients. Pediatr Blood Cancer 2014;61: 2004–2011. © 2014 Wiley Periodicals, Inc.

Key words: brain cancer; end-of-life; neuro-oncology; palliative care; pediatric oncology; supportive therapy

Perdita di relazione

Irreversibilità

Responsabilità

Prima conferma della perdita imminente

Criticità

Ethical Issues in Palliative Care

Ethical Considerations in the Management of Analgesia in Terminally Ill Pediatric Patients

Norbert J. Weidner, MD, and Diane M. Plantz, MD, MA

Division of Pain and Palliative Medicine, Cincinnati Children's Hospital Medical Center (N.J.W.), Cincinnati, Ohio; and Children's Mercy Hospital (D.M.P.), Kansas City, Missouri, USA

Abstract

Research has demonstrated the significant symptom burden present at the end of life of terminally ill children. Medicine has always viewed the relief of pain and suffering as a fundamental human right and a moral and ethical obligation. At the end of life, pain and dyspnea are symptoms commonly experienced by both adults and children. Opioids are the mainstay in treating the suffering associated with pain and dyspnea; however, there exist several barriers to the use of opioids. We describe a case in which parents prevent a young patient from receiving adequate pain management during the course of a terminal illness. We discuss the importance of recognizing the barriers to opioid use and the ethical ramifications of failing to find common ground with the family. We highlight parental responsibilities and limitations of parental authority in decision making for their child. J Pain Symptom Manage 2014;48:998–1003. *© 2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Right to pain relief, parental refusal of treatment in a minor, parental authority for decision making for a minor

Dubbi

Please Do Whatever It Takes to End Our Daughter's Suffering!

Stéphan Clément de Cléty, MD,[a] Marie Friedel, RN, PNP, MSc,[b] A.A. Eduard Verhagen, MD, JD, PhD,[c] John D. Lantos, MD,[d] Brian S. Carter, MD[d]

What is the best way to care for a child with severe neurologic impairment who seems to be dying and is in intractable pain? Can we give sedation as we remove life support? Is it ethically permissible to hasten death? In the United States, 5 states have legalized assisted suicide (although only for competent adults). In Belgium and the Netherlands, euthanasia is legal for children under some circumstances. We present a case in which parents and doctors face difficult decisions about palliative care. Experts from Belgium, the Netherlands, and the United States then discuss how they would respond to such a case.

Medical technology allows us to sustain the lives of people with profound neurologic impairment. In some cases, survivors experience intractable pain or discomfort. In such cases, family members and doctors may agree that continued use of life-sustaining interventions (LSI) is no longer appropriate. Then another series of decisions follows. What is the best way to care for a child as he or she is dying? In the United States, 5 states have legalized assisted suicide (although only for competent adults). In Belgium and the Netherlands, euthanasia is legal for children under some circumstances. We present a case in which a critically ill child has apparent intractable pain. We asked experts from the United States, Belgium, and the Netherlands to discuss how they would respond to such a case.

THE CASE

A 12-year-old child with anoxic encephalopathy after a near-drowning event at age 2 years develops viral meningitis and is rehospitalized in the PICU. After 21 days, she remains on assisted ventilation via her tracheostomy; her parents are concerned that she is not responsive and has not returned to baseline. She has daily episodes of agitation, hyperpyrexia, hypertension, hypoxemia, and dystonia, and she appears to be in pain to both her parents and the ICU team. In addition, she has new-onset seizure activity. None of these signs improve after a medically induced state of deep sedation is lifted.

Her parents approach the PICU team after daily rounds and state, "This is unbearable to watch and endure after the past 10 years of caring for her. If she cannot be made comfortable, and you cannot make her pain go away, what can you do?" The team asks about her baseline status. "She needs suctioning of her tracheostomy every 1 to 2 hours, she smiles and responds to our voices and our gentle touch; she likes music." The PICU team remarks that her chest film is clear, her oxygen requirement is nil, and her apparent seizures are controlled, but her respiratory drive is poor and her electroencephalogram demonstrates persistent electrographic seizure activity. Her agitation, seizures, and respiratory insufficiency appear to require deep sedation. The neurologist

[a]Cliniques universitaires St Luc, Université catholique de Louvain, Brussels, Belgium; [b]Haute Ecole Vinci and Université catholique de Louvain, Brussels, Belgium; [c]Beatrix Children's Hospital, University Medical Center Groningen, University of Groningen, Groningen, Netherlands; and [d]Children's Mercy Hospital and University of Missouri, Kansas City, Missouri

Dr Clément de Cléty, Ms Friedel, and Drs Verhagen, Lantos, and Carter contributed to the article design and to the drafting and review of the manuscript; all authors approved the final version.

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Address correspondence to John D. Lantos, MD, Children's Mercy Hospital, 2401 Gillham Rd, Kansas City, MO 64108. E-mail: jlantos@cmh.edu

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Dubbi

ETHICS ROUNDS

Are We Allowed to Discontinue Medical Treatment in This Child?

Wendela G. Leeuwenburgh-Pronk, MD[a], Laura Miller-Smith, MD[b], Vicki Forman, RN[c], John D. Lantos, MD[b], Dick Tibboel, MD, PhD[a], Corinne Buysse, MD, PhD[a]

abstract

One of the most difficult ethical dilemmas in pediatrics today arises when a child has complex chronic conditions that are not curable and cause discomfort with no prospect of any improvement on quality of life. In the context of medical futility, it is harmful to prolong medical treatment. The question is: How can medical treatment be discontinued when the child is not dependent on mechanical ventilation or ICU treatment? What is the appropriate palliative care and does it justify the use of sedatives or analgesics if this also might shorten life?

One of the most difficult ethical dilemmas in pediatrics today arises when a child has complex chronic conditions that are not curable and cause discomfort with no prospect of any improvement on quality of life. In the context of medical futility, it is harmful to prolong medical treatment. The question is: How can medical treatment be discontinued when the patient is not dependent on mechanical ventilation or ICU treatment? What is considered proper palliative care and does it justify the use of sedatives or analgesics if this also might shorten life?

We present such a case and seek commentary from experts with experience in such difficult cases. Laura Miller-Smith is a pediatric intensivist at Children's Mercy Hospital in Kansas City, Missouri. Vicki Forman is a nurse at Verdugo Hills Hospital in Glendale, California, and the author of *This Lovely Life: A Memoir of Premature Motherhood* (2009). Wendela Leeuwenburgh-Pronk is a pediatrician, currently working at Emma Children's Hospital in Amsterdam. Dick Tibboel and Corinne Buysse are pediatric intensivists at the Sophia Children's Hospital in Rotterdam, Netherlands. They were the physicians involved in the case. The parents consented to publication of the case.

THE CASE

Anna was born at term after an uneventful pregnancy. At birth she was diagnosed with Down syndrome, a small atrial septal defect type II, and respiratory distress due to stenosis of the choanae. Anna's parents welcomed her into their life, never questioning the quality of life for and with a disabled child. During infancy, Anna developed multiple mysterious problems that seemed unrelated to the Down syndrome. She had feeding problems with the constant urge to vomit. The cause of these problems was unknown.

At the age of 7 months, a gastrostomy and jejunostomy were placed, which alleviated her symptoms only mildly. She had intermittent severe respiratory distress, thought to be due to a combination of laryngotracheomalacia and severe obstructive sleep apnea due to stenosis of the choanae and hypotonia.

At age 9 months, she remained dependent on oxygen supplementation and noninvasive positive-pressure respiratory support. A tracheotomy alleviated the symptoms of obstructive sleep apnea syndrome, but Anna

[a]Sophia Children's Hospital, Erasmus Medical Centre, Rotterdam, Netherlands; [b]Children's Mercy Hospital, Kansas City, Missouri; and [c]Verdugo Hills Hospital, Glendale, California

Drs Leeuwenburgh-Pronk, Miller-Smith, Lantos, Tibboel, Buysse, and Ms Forman helped conceptualize the project and contributed to the manuscript; and all authors reviewed and approved the final manuscript as submitted.

Dr Leeuwenburgh-Pronk's current affiliation is Emma Children's Hospital, Academic Medical Centre, Amsterdam, Netherlands.

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Address correspondence to Wendela G. Leeuwenburgh, MD, Department of Pediatrics, Emma Children's Hospital, PO Box 22660,1100 DD Amsterdam, The Netherlands. E-mail: w.g.leeuwenburgh@amc.uva.nl

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	EUTANASIA	SEDAZIONE PALLIATIVA
OBIETTIVO	Morte del paziente	Controllo dei sintomi
FARMACI E DOSAGGI	Adeguati a provocare la morte	Adeguati al controllo dei sintomi
RISULTATO	Morte	Controllo dei sintomi

Dubbi

Effect of continuous deep sedation on survival in patients with advanced cancer (J-Proval): a propensity score-weighted analysis of a prospective cohort study

Isseki Maeda, Tatsuya Morita, Takuhiro Yamaguchi, Satoshi Inoue, Masayuki Ikenaga, Yoshihisa Matsumoto, Ryuichi Sekine, Takashi Yamaguchi, Takeshi Hirohashi, Tsukasa Tajima, Ryohei Tatara, Hiroaki Watanabe, Hiroyuki Otani, Chizuko Takigawa, Yoshinobu Matsuda, Hiroka Nagaoka, Masanori Mori, Yo Tei, Ayako Kikuchi, Mika Baba, Hiroya Kinoshita

Summary

Background Continuous deep sedation (CDS) before death is a form of palliative sedation therapy that has become a focus of strong debate, especially with respect to whether it shortens survival. We aimed to examine whether CDS shortens patient survival using the propensity score-weighting method, and to explore the effect of artificial hydration during CDS on survival.

Methods This study was a secondary analysis of a large multicentre prospective cohort study that recruited and followed up patients between Sept 3, 2012, and April 30, 2014, from 58 palliative care institutions across Japan, including hospital palliative care settings, inpatient palliative care units, and home-based palliative care services. Adult patients (aged ≥20 years) with advanced cancer who received care through the participating palliative care services were eligible for this secondary analysis. Patients with missing data for outcome variables or who lived for more than 180 days were excluded. We compared survival after enrolment between patients who did and did not receive CDS. We used a propensity score-weighting method to control for patient characteristics, disease status, and symptom burden at enrolment.

Findings Of 2426 enrolled patients with advanced cancer, we excluded 289 (12%) for living longer than 180 days and 310 (13%) with missing data, leaving an analysis population of 1827 patients. 269 (15%) of 1827 patients received CDS. Unweighted median survival was 27 days (95% CI 22–30) in the CDS group and 26 days (24–27) in the no CDS group (median difference −1 day [95% CI −5 to 4]; HR 0·92 [95% CI 0·81–1·05]; log-rank p=0·20). After propensity-score weighting, these values were 22 days (95% CI 21–24) and 26 days (24–27), respectively (median difference −1 day [95% CI −6 to 4]; HR 1·01 [95% CI 0·87–1·17]; log-rank p=0·91). Age ($p_{interaction}$=0·67), sex ($p_{interaction}$=0·26), performance status ($p_{interaction}$=0·90), and volume of artificial hydration ($p_{interaction}$=0·14) did not have an effect modification on the association between sedation and survival, although care setting did have a significant effect modification ($p_{interaction}$=0·021).

Interpretation CDS does not seem to be associated with a measurable shortening of life in patients with advanced cancer cared for by specialised palliative care services, and could be considered a viable option for palliative care in this setting.

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See Comment page 15

Department of Palliative Medicine, Osaka University Graduate School of Medicine, Suita, Osaka, Japan (I Maeda MD); Department of Palliative and Supportive Care, Palliative Care Team (T Morita MD), and Seirei Hospice (T Morita, S Inoue MD, Y Tei MD), Seirei Mikatahara General Hospital, Kita-ku, Hamamatsu, Shizuoka, Japan; Division of Biostatistics, Tohoku University Graduate School of Medicine, Aoba-ku, Sendai, Miyagi, Japan (Prof Taku Yamaguchi PhD); Children's Hospice Hospital, Yodogawa Christian Hospital, Higashiyodogawa-ku, Osaka, Japan (M Ikenaga MD); Department of Palliative Medicine, National Cancer Center Hospital East, Kashiwa, Chiba, Japan (Y Matsumoto MD, H Kinoshita MD); Department of Pain and Palliative Care, Kameda Medical Center, Kamogawa, Chiba, Japan (R Sekine MD); Department of Palliative Medicine, Kobe University Graduate School of Medicine, Kobe, Hyogo, Japan (Taku Yamaguchi MD); Department of Palliative Care, Mitui Memorial Hospital, Chiyoda-ku, Tokyo, Japan (T Hirohashi MD); Department of Palliative Medicine, Tohoku University Hospital, Sendai, Miyagi, Japan (T Tajima MD); Department of Palliative Medicine, Osaka City General Hospital, Miyakojima-ku, Osaka, Japan (R Tatara MD); Komaki City Hospital, Komaki, Aichi, Japan (H Watanabe MD); Department of Palliative Care Team, and Palliative and Supportive Care, National

Introduction

Patients nearing death often have distressing symptoms.[1] Despite advances in palliative medicine, some symptoms are refractory to intensive palliative care and palliative sedation therapy is used.[2,3] The concept of palliative sedation therapy was initially introduced in the early 1990s, and academic associations worldwide have since clarified definitions and developed clinical guidelines.[4–6]

Continuous deep sedation until death (CDS) is a type of palliative sedation therapy. It is more controversial than other types of palliative sedation therapy with respect to many aspects, including whether it shortens patient survival, especially when provided without artificial hydration therapy, and whether the physician's intent is purely symptom palliation.[7,8] CDS might be potentially life shortening as a result of concomitant withholding of artificial hydration, pharmacological effects of high-dose sedatives on the respiratory and circulation system, or both. For evidence-based discussion, the clarification of whether CDS, not palliative sedation therapy as a whole, shortens patient survival is of great value.

Until now, many empirical studies have addressed the potential effect of palliative sedation therapy on patient survival.[8–10] A systematic review[8] identified no significant differences in survival between patients who were sedated and those who were not. However, these previous studies had many limitations. First, the definition of sedation varied, and few studies specifically investigated CDS. Second, patients were recruited from one or a few selected institutions, and therefore the generalisability is limited. Third, except for one matched-cohort study,[11] known prognostic factors were not adjusted for. Finally, no published research has addressed the effects of

Dispnea
Sintomi neurologici
Dolore

Inalazione
Emorragia
Aritmia

refrattari

Affrontare il problema precocemente già alla presa in carico in alcune situazioni

Risposta in Equipe

Condivisione senza ossessione

Rispettare i tempi quando possibile

Affrontare il problema in maniera allargata

Valutare sempre il percepito del bambino

Parlare con il bambino e raccogliere i suoi desideri

Rispondere alle domande (anche quelle non fatte)

In acuto

Prevedere evenienza
Preparare FC di gestione e mettere a disposizione farmaci adeguati
Definire le situazione
Educare all’utilizzo

Sedazione

OPPIOIDI (bolo con poi infusione continua - Morfina)

SEDATIVI (Benzodiazepine (Midazolam in infusione continua da 0.05 a 0.2 mg e più /Kg/ora)

NEUROLETTICI

Diminuire ventilazione assistita

Oppiacei

	Tipo	Vie	Dose
Oppioidi deboli	Codeina	os/rett.	0,5-1 mg/kg ogni 4-6-8 h
	Tramadolo	os	0,5-1 mg/kg ogni 4-6-8 h
		ev	1 mg/kg ogni 3-4 h; i.c. 0,3 mg/kg/h
Oppioidi forti	Oxicodone cloridrato	os	0,1-0,2 mg/kg ogni 8-12 h
	Morfina solfata rapido rilascio	os	0,15-0,3 mg/kg ogni 4 h
	Morfina solfata lento rilascio	os	0,3-0,6 mg/kg ogni 8-12 h
	Morfina cloridrato	ev	Bolo 0,05-0,1 og mg/kg ogni 2-4 h; i.c. 0,02-0,03 mg/kg/h
	Fentanile	ev	bolo 0,001-0,002 µg/kg/h (max 5 gamma/kg in respiro spontaneo), i.c. 0,001 µg/kg/h
	Metadone	os	0,05-0,1 mg/kg ogni 8-12 h (schema posologico da modificare in rapporto alla durata della terapia)

Midazolam

• Meccanismo d'azione: depressore dell'SNC con attività sedativa, antiansiogena, antiepilettica, miorilassante.
Azione GABA-potenziante nel SNC

• Farmacologia: benzodiazepina a breve durata d'azione
EV: effetto immediato-rapido

• Emivita plasmatica d'eliminazione: 2 ÷ 5 ore.

Dexmedetomidine for Sedation during Withdrawal of Support

Chris O'Hara, Robert F. Tamburro and Gary D. Ceneviva

Penn State Milton S. Hershey Medical Center, Penn State College of Medicine, Penn State Hershey Children's Hospital, Department of Pediatrics, Hershey, PA, USA.

ABSTRACT: Agents used to control end-of-life suffering are associated with troublesome side effects. The use of dexmedetomidine for sedation during withdrawal of support in pediatrics is not yet described. An adolescent female with progressive and irreversible pulmonary deterioration was admitted. Despite weeks of therapy, she did not tolerate weaning of supplemental oxygen or continuous bilevel positive airway pressure. Given her condition and the perception that she was suffering, the family requested withdrawal of support. Despite opioids and benzodiazepines, she appeared to be uncomfortable after support was withdrawn. Ketamine was initiated. Relief from ketamine was brief, and its use was associated with a "wide-eyed" look that was distressing to the family. Ketamine was discontinued and a dexmedetomidine infusion was initiated. The patient's level of comfort improved greatly. The child died peacefully 24 hours after initiating dexmedetomidine from her underlying disease rather than the effects of the sedative.

KEYWORDS: palliative care, hypnotics and sedatives, dexmedetomidine, lung disease

CITATION: O'Hara et al. Dexmedetomidine for Sedation during Withdrawal of Support. *Palliative Care: Research and Treatment* 2015:9 15–18 doi:10.4137/PCRT.S27954.

TYPE: Case Report

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CORRESPONDENCE: cohara1@hmc.psu.edu

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Possono essere d’aiuto

Fentanil transmucoso – Dolore incidente

Scopolamina trasdermica – Ridurre le secrezioni

N-butilbromuro di joscina – Riduzione dei vomiti

Furosemide – Edema – Dispnea

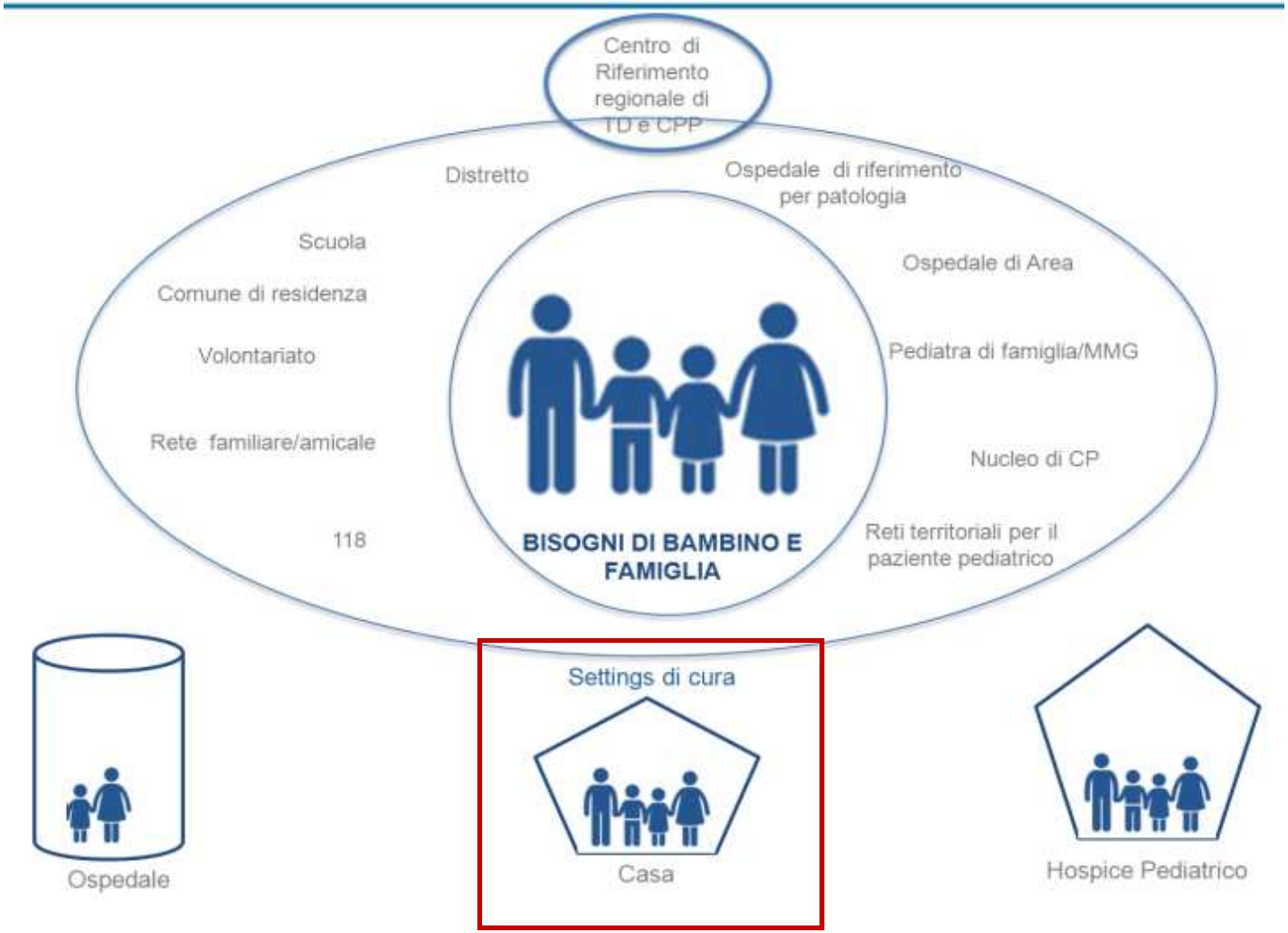
Best practice

Prevedere uso di boli di farmaci
Prevedere la non-scarsa risposta al trattamento
Individuare tecniche non farmacologiche adeguate
Setting tranquillo
Rispetto dei desideri di bambino e famiglia

Vie di somministrazione

Endovenosa più efficace ed immediata
OS/SNG/PEG utilizzabile ma lenta e biodisponibilità non prevedibile
Nasale utile nella gestione in emergenza
Rettale efficace ma indaginosa e percepita come invasiva
Transmucosa utile ma con biodisponibilità non sempre prevedibile
Sottocute pochissime segnalazioni e dipendente dal paziente
Areosolica nessuna conferma in età pediatrica

dove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Distretto
Ospedale di riferimento per patologia
Scuola
Comune di residenza
Volontariato
Rete familiare/amicale
118
Ospedale di Area
Pediatra di famiglia/MMG
Nucleo di CP
Reti territoriali per il paziente pediatrico
BISOGNI DI BAMBINO E FAMIGLIA
Settings di cura
Ospedale
Casa
Hospice Pediatrico

Brief Report

Palliative Sedation at Home for Terminally Ill Children With Cancer

Aleksandra Korzeniewska-Eksterowicz, MD, PhD, Łukasz Przysło, MD, PhD, Wojciech Fendler, MD, PhD, Małgorzata Stolarska, MD, PhD, and Wojciech Młynarski, MD, PhD

Pediatric Palliative Care Unit (A.K.-E., Ł.P.), Department of Pediatrics, Oncology, Hematology and Diabetology, Medical University of Lodz; Gajusz Foundation (A.K.-E., Ł.P., M.S.), Pediatric Palliative Care Center - Home Hospice for Children of Lodz Region; and Department of Pediatrics, Oncology, Hematology and Diabetology (W.F., M.S., W.M.), Medical University of Lodz, Lodz, Poland

Dove

Abstract

Context. The presence of symptoms that are difficult to control always requires adjustment of treatment, and palliative sedation (PS) should be considered.

Objectives. We analyzed our experience in conducting PS at home for terminally ill children with cancer during a seven-year period.

Methods. We performed a retrospective analysis of medical records of children with cancer treated at home between the years 2005 and 2011.

Results. We analyzed the data of 42 cancer patients (18% of all patients); in 21 cases, PS was initiated (solid tumors $n = 11$, brain tumors [5], bone tumors [4], leukemia [1]). Sedation was introduced because of pain ($n = 13$), dyspnea (9), anxiety (5), or two of those symptoms (6). The main drug used for sedation was midazolam; all patients received morphine. There were no significant differences in the dose of morphine or midazolam depending on the patient's sex; age was correlated with an increase of midazolam dose ($R = 0.68$; $P = 0.005$). Duration of sedation ($R = 0.61$; $P = 0.003$) and its later initiation ($R = 0.43$; $P = 0.05$) were correlated with an increase of the morphine dose. All patients received adjuvant treatment; in patients who required a morphine dose increase, metoclopramide was used more often ($P = 0.0002$). Patients did not experience any adverse reactions. Later introduction of sedation was associated with a marginally higher number of intervention visits and a significantly higher number of planned visits ($R = 0.53$; $P = 0.013$).

Conclusion. Sedation may be safely used at home. It requires close monitoring and full cooperation between the family and hospice team. Because of the limited data on home PS in pediatric populations, further studies are needed. J Pain Symptom Manage 2014;48:968–974. © 2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

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End of life care sedation for children.

Kiman R[1], Wuiloud AC, Requena ML.

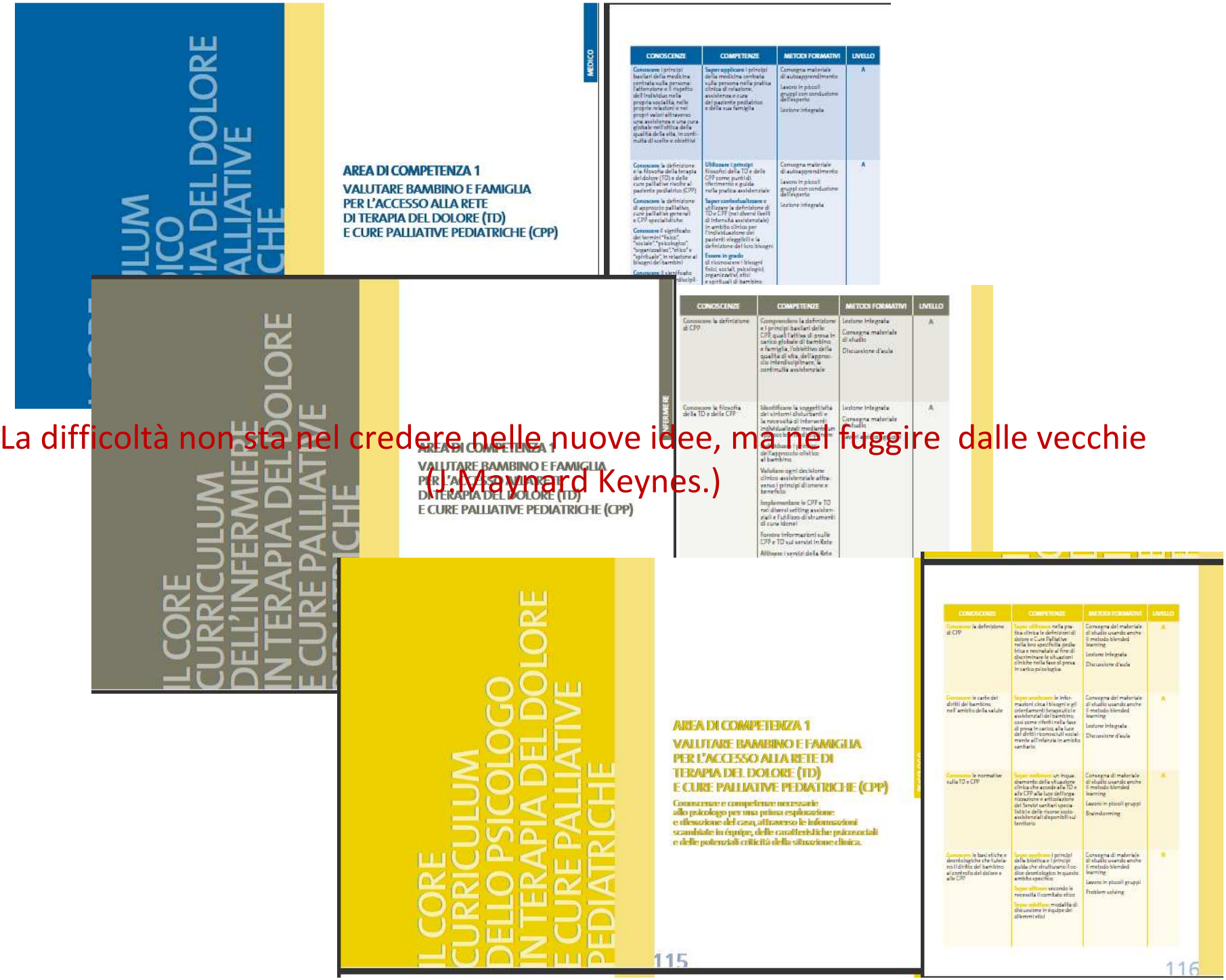
Author information

Abstract

PURPOSE OF REVIEW: This article is aimed to review updated research on end-of-life care sedation (EOLC-S) for children and aspects surrounding this issue.

RECENT FINDINGS: Prevalence of EOLC-S for children may vary across countries on account of cultural differences, in terms of settings, legal issues and perceptions about EOLC-S, which lead to variation in patient selection and management. Although home is the preferred place of death for families, research shows hospital settings and ICUs to be the most frequent places where children die. Data on how to define refractory symptoms and update research on drug selection and dosing are lacking. Nature of symptoms at end of life (EOL) is described for cancer patients, but few articles focused on nononcological conditions. Decision making at EOL is commonly discussed with families but children are less frequently involved.

SUMMARY: A thorough search of databases was conducted for articles published in the last year. We found few articles describing EOLC-S as a last resort. But how, when and by whom a symptom is defined as refractory, is not well established. Aggressive symptom management at EOL along with advanced care planning conducted by pediatric palliative care teams could diminish EOLC-S. More research is needed.



La difficoltà non sta nel credere nelle nuove idee, ma nel fuggire dalle vecchie

(J.Maynard Keynes.)

Human Rights Watch

Perché le cose cambiano realmente con il nostro esempio e non con la nostra opinione