

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).

Quando?

Quali Bambini ?

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

Quando nella storia di malattia?

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 oncologiche 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 threatening*”**

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 threatening*”

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



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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



Quando?

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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

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

A diagram of a soccer field with a central circle and two goal areas. The field is divided into two halves by a vertical line. The left half contains the labels 'SOSTEGNO' at the top, 'SUPERVISIONE' in the middle, and 'RUOLO' at the bottom. The right half contains the labels 'FORMAZIONE' at the top, 'SUPPORTO' in the middle, and 'RISORSE' at the bottom. The labels 'SUPERVISIONE' and 'SUPPORTO' are in red, while the others are in gray.

SOSTEGNO

SUPERVISIONE

RUOLO

FORMAZIONE

SUPPORTO

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

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

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Definizione

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

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

End-of-Life Care in Pediatric Neuro-Oncology

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and Franca Fagioli, MD¹

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

paure

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

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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

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

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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

abstract

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Are We Allowed to Discontinue Medical Treatment in This Child?

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Dubbi

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?

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 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

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Dr. 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.

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Dubbi

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

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 Nagaoaka, 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 ($p_{\text{interaction}}=0.67$), sex ($p_{\text{interaction}}=0.26$), performance status ($p_{\text{interaction}}=0.90$), and volume of artificial hydration ($p_{\text{interaction}}=0.14$) did not have an effect modification on the association between sedation and survival, although care setting did have a significant effect modification ($p_{\text{interaction}}=0.021$).

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.

Funding Japanese National Cancer Center Research and Development Fund.

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.^{4,5}

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.^{9–17} A systematic review⁸ 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

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See Comment page 15

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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	Oxycodone 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 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, antiansiogenica, antiepilettica, miorilassante.

Azione GABA-potenziante nel SNC

- Farmacologia: benzodiazepina a breve durata d'azione
EV: effetto immediato-rapido
- Emivita plasmatica d'eliminazione: $2 \div 5$ 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
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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-scarso 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

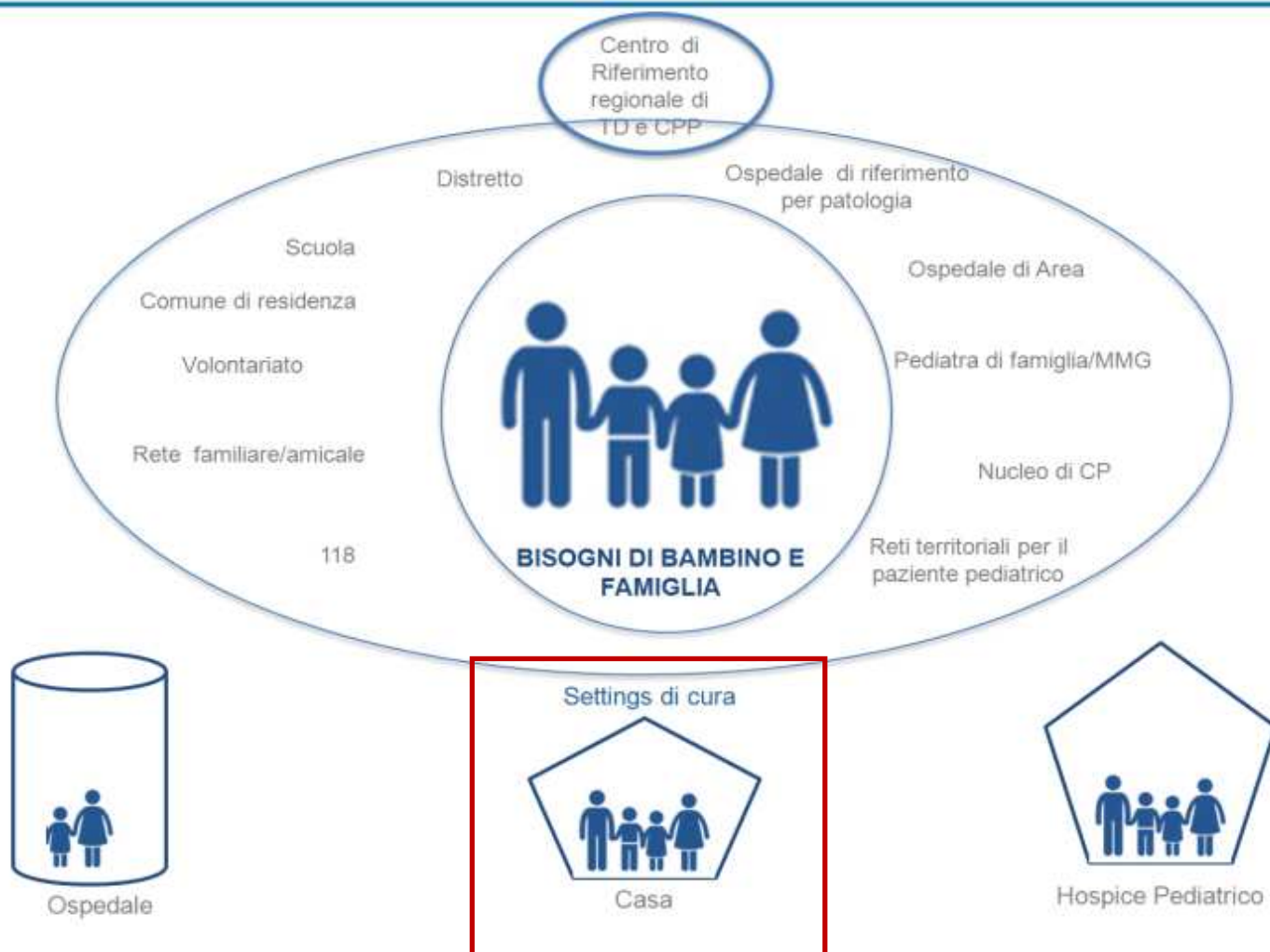
Rettale efficace ma indaginoso e percepito come invasivo

Transmucosa utile ma con biodisponibilità non sempre prevedibile

Sottocute pochissime segnalazioni e dipendente dal paziente

Aerosolica nessuna conferma in età pediatrica

dove



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., L.P.), Department of Pediatrics, Oncology, Hematology and Diabetology, Medical University of Lodz; Gajusz Foundation (A.K.-E., L.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.

End of life care sedation for children.

Kimani R¹, Wuioud 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 (Maynard Keynes.)

MEDICO

AREA DI COMPETENZA 1 VALUTARE BAMBINO E FAMIGLIA PER L'ACCESSO ALLA RETE DI TERAPIA DEL DOLORE (TD) E CURE PALLIATIVE PEDIATRICHE (CPP)

CONOSCENZE	COMPETENZE	METODI FORMATIVI	LIVELLO
Conoscere i principi basilari della medicina palliativa sulle persone: l'attenzione e il rispetto dell'individuo nella propria società, nelle proprie relazioni e nei propri valori etici; avere una visione e una cura globale nell'ottica della qualità della vita, in continuità di scelte e obiettivi.	Saper applicare i principi della medicina palliativa sulla persona nella pratica clinica di relazione, assistenza e cura del paziente pediatrico e della sua famiglia.	Consegna materiale di autoapprendimento; lavoro in piccoli gruppi con conduzione dell'insegnante; lezione integrata.	A
Conoscere la definizione e la filosofia della terapia del dolore (TD) e delle cure palliative rivolte al paziente pediatrico (CPP).	Utilizzare i principi filosofici della TD e delle CPP come punti di riferimento e guida nella pratica assistenziale.	Consegna materiale di autoapprendimento; lavoro in piccoli gruppi con conduzione dell'insegnante; lezione integrata.	A
Conoscere la definizione di approccio palliativo, cure palliative generali e CPP specialistiche.	Saper confrontare e utilizzare la definizione di TD e CPP (nei diversi livelli di intensità assistenziale) in ambito clinico per l'individuazione dei pazienti eleggibili e la definizione del loro bisogno.		
Conoscere il significato dei termini "fisico", "sociale", "psicologico", "funzionamento", "etico" e "spirituale" in relazione ai bisogni del bambino.	Essere in grado di riconoscere bisogni fisici, sociali, psicologici, organizzativi, etici e spirituali di bambino.		
Conoscere il significato dei termini "fisico", "sociale", "psicologico", "funzionamento", "etico" e "spirituale" in relazione ai bisogni del bambino.			

CONOSCENZE	COMPETENZE	METODI FORMATIVI	LIVELLO
Conoscere la definizione di CPP.	Comprendere la definizione di CPP quali attività di presa in carico globale di bambino e famiglia, l'obiettivo della qualità di vita, dell'approccio interdisciplinare, la continuità assistenziale.	Lezione Integrata di studio; Consegna materiale di studio; Discussione d'aula.	A
Conoscere la filosofia della TD e delle CPP.	Identificare la soggettività dei sintomi da trattare e le necessità di interventi individualizzati, prendendo in considerazione l'aspetto dell'approccio olistico al bambino.	Lezione Integrata di studio; Consegna materiale di studio.	A
	Valutare ogni decisione clinica assistenziale alla luce dei principi di etica e beneficio.		
	Implementare le CPP e TD nei diversi setting assistenziali e l'utilizzo di strumenti di cura idonei.		
	Fornire informazioni sulle CPP e TD sui servizi in Rete.		
	Attivare i servizi della Rete.		

AREA DI COMPETENZA 1 VALUTARE BAMBINO E FAMIGLIA PER L'ACCESSO ALLA RETE DI TERAPIA DEL DOLORE (TD) E CURE PALLIATIVE PEDIATRICHE (CPP)

Conoscenze e competenze necessarie allo psicologo per una prima esplorazione e rilevazione del caso, attraverso le informazioni secondarie in équipe, delle caratteristiche psico-sociali e delle potenziali criticità della situazione e clinica.

CONOSCENZE	COMPETENZE	METODI FORMATIVI	LIVELLO
Conoscere la definizione di CPP.	Saper utilizzare nella pratica clinica le definizioni di dolore e Cure Palliative nella loro specificità pediatrica e ricorrendo al fine di distinguere le situazioni cliniche nella fase di presa in carico psicologica.	Consegna del materiale di studio usando anche il metodo blended learning; Lezione Integrata; Discussione d'aula.	A
Conoscere le carte dei diritti del bambino nell'ambito della salute.	Saper utilizzare le informazioni circa bisogni e gli orientamenti terapeutici e assistenziali del bambino, così come riferiti nella fase di presa in carico, alla luce dei diritti riconosciuti socialmente all'infanzia in ambito sanitario.	Consegna del materiale di studio usando anche il metodo blended learning; Lezione Integrata; Discussione d'aula.	A
Conoscere le normative sulla TD e CPP.	Saper conoscere un inquadramento della situazione clinica che accede alla TD e alla CPP alla luce dell'organizzazione e attivazione dei Servizi sanitari specializzati della rete socio-assistenziale disponibili sul territorio.	Consegna di materiale di studio usando anche il metodo blended learning; Lavoro in piccoli gruppi; Brainstorming.	A
Conoscere le basi etiche e deontologiche che tutelano i diritti del bambino al controllo del dolore e alla CPP.	Saper applicare i principi della bioetica e i principi guida che strutturano il lavoro degli operatori in questo ambito specifico.	Consegna di materiale di studio usando anche il metodo blended learning; Lavoro in piccoli gruppi; Problem solving.	B
	Saper definire secondo le necessità il formato etico.		
	Saper utilizzare modalità di discussione in équipe dei dilemmi etici.		

THE LANCET

unemployed according to the Italian statistics bureau, known as ISTAT) have been associated with reduced birth rate and increased women's age at childbirth. According to ISTAT, in 2012 there were 534 185 infants born in Italy—about 17 000 fewer than in 2002 and about 47 000 fewer than in 2008 (a 7·4% decrease between 2008 and 2012).¹ The provisional data for 2013 show a further 4·3% decrease in birth rate. The decrease in fertility rate is more pronounced in Italian women: fertility rate in 2012 was 1·42, 1·29 for Italian women and 2·37 for foreign women. Furthermore, there has also been an increase in the age of Italian women: the highest in the EU with 34·7% of women 35 years or older.² Infant mortal progressively declines 3·2 per 1000 live births although there are infant mortality rates higher in the poorest according to ISTAT to women living in conditions (eg, little access to pre-natal care, risk of disease).³ Worst poverty is increased even during this economic crisis and social exclusion deterioration in the outcomes.

A charter for the rights of the dying child

The death of a child is a devastating experience for all those involved.

European. The European perinatal health report 2012. <http://www.europerinatalhealth.org/2012-report> (accessed April 14, 2014).

1. The Centre for Monitoring Income and Social Policy. <http://www.cmis.it/> (accessed April 14, 2014).

2. The Centre for Monitoring Income and Social Policy. <http://www.cmis.it/> (accessed April 14, 2014).

3. The Centre for Monitoring Income and Social Policy. <http://www.cmis.it/> (accessed April 14, 2014).

It is certainly not an easy problem to address, since the factors conditioning and influencing behaviour and choices are complex and deep-rooted. However, the difficulties encountered in addressing this problem cannot hinder the undertaking nor generate doubts and misgivings regarding the rights of these children and the duties of those accompanying and caring for them during the final phase of their life.

In September, 2013, a group of 15 individuals working with children affected by incurable illness in Italy launched a request, supported and

for 2013 and 2014 (see endnote 1).



Medaglia d'Oro
al merito della
Sanità Pubblica
2013

CARTA DEI DIRITTI DEL BAMBINO MORENTE CARTA DI TRIESTE

Human Rights Watch



Correspondence

developed in four steps: extensive review of the literature; the preparation of a first draft of the Rights of the Dying Child; revision of this draft by a larger group of 50 experts representative of a range of professional, institutional, and social figures (doctors, nurses, psychologists, philosophers, ethicists, parents and journalists) at a consensus meeting held in Trieste, Italy; and finally the integration of comments and feedback, and finalisation and approval of the definitive version of the bill of rights entitled the Trieste Charter.

The charter proposes ten fundamental rights for children who are terminally ill. The charter was developed in four steps: extensive review of the literature; the preparation of a first draft of the Rights of the Dying Child; revision of this draft by a larger group of 50 experts representative of a range of professional, institutional, and social figures (doctors, nurses, psychologists, philosophers, ethicists, parents and journalists) at a consensus meeting held in Trieste, Italy; and finally the integration of comments and feedback, and finalisation and approval of the definitive version of the bill of rights entitled the Trieste Charter.

The charter will have achieved its purpose when every individual caring for a dying child will be capable of staying near the child until the last moments of his or her life, prepared to accept his or her death, ensuring both respect and dignity.

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1. UN Declaration of the Rights of the Child (1959) General Assembly, New York, 1959; <http://www.un.org/en/children/declaration.shtml> (accessed April 15, 2014).
2. Council of Europe Committee of Ministers, Declaration of the Rights of the Child (1959), http://www.coe.int/t/t49/declaration_of_the_rights_of_the_child/declaration_of_the_rights_of_the_child.asp (accessed April 15, 2014).
3. European Union Charter of Fundamental Rights (2000), <http://www.europa.eu/charter/fundamental-rights> (accessed April 15, 2014).
4. European Union Charter of Fundamental Rights (2000), <http://www.europa.eu/charter/fundamental-rights> (accessed April 15, 2014).
5. European Union Charter of Fundamental Rights (2000), <http://www.europa.eu/charter/fundamental-rights> (accessed April 15, 2014).
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9. European Union Charter of Fundamental Rights (2000), <http://www.europa.eu/charter/fundamental-rights> (accessed April 15, 2014).
10. European Union Charter of Fundamental Rights (2000), <http://www.europa.eu/charter/fundamental-rights> (accessed April 15, 2014).

Global elderly care in crisis: a view from Japan

I read with interest The Lancet's editorial (March 15, p 927) discussing the increase in demand for elderly care and how the UK and other countries are trying to cope with the situation.

With more hospital beds (13·6 per 1000 individuals) and a far longer average length of stay (37·5 days) compared with other countries from the Organisation for Economic Co-operation and Development, Japan is also making efforts to manage and sustain its elderly care system in presence of growing demands. The Japanese government has been implementing a series of measures to support elderly care facilities and personnel before the introduction of public long-term care insurance in 2000. These measures were to help elderly people live more independently, relieve the burden of family caring, and also facilitate transfer of elderly people from costly unnecessary hospital care into the long-term care system.¹

Today 25% of the Japanese population is older than 65 years. Policies are strategically aiming to both providing integrated care within the community. Disease prevention and health promotion are key to these policies. For securing sustainability of elderly care, finding the optimal balance of service use with containment of public expenditure is a huge challenge.

Some countries in the Association of Southeast Asian Nations (ASEAN) are expected to have more rapidly ageing population than Japan.² To share our experiences with ASEAN countries, the Ministry of Health, Labour and Welfare formed the study group for Japan's International Contribution to Active Aging, which I had the opportunity to chair. The group recently issued a report on user-oriented strategies for international cooperation in elderly care and might provide useful information for other countries with rapidly ageing populations.³

The report gives an overview of ageing in ASEAN countries, a brief outline of the history of Japanese ageing policies, and current and future possible cooperations for each ASEAN country with Japan—including policy planning, human resource development, and measures for non-communicable disease prevention.

I declare that I have no competing interests.

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Patel et al. (pages 1–6, November 14, 2013) in the programme of common mental disorders in children and adolescents is a 25 year period in which it is likely that the prevalence of common mental disorders (CMD) in the general population of the United Kingdom, for which point in time the 12 new General Health Questionnaire (GHQ) items have been used, is around 10–15%.¹ The prevalence has been made in the online version of May 1, 2014.

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