PALLIATIVE SEDATION THERAPY

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PALLIATIVE SEDATION THERAPY

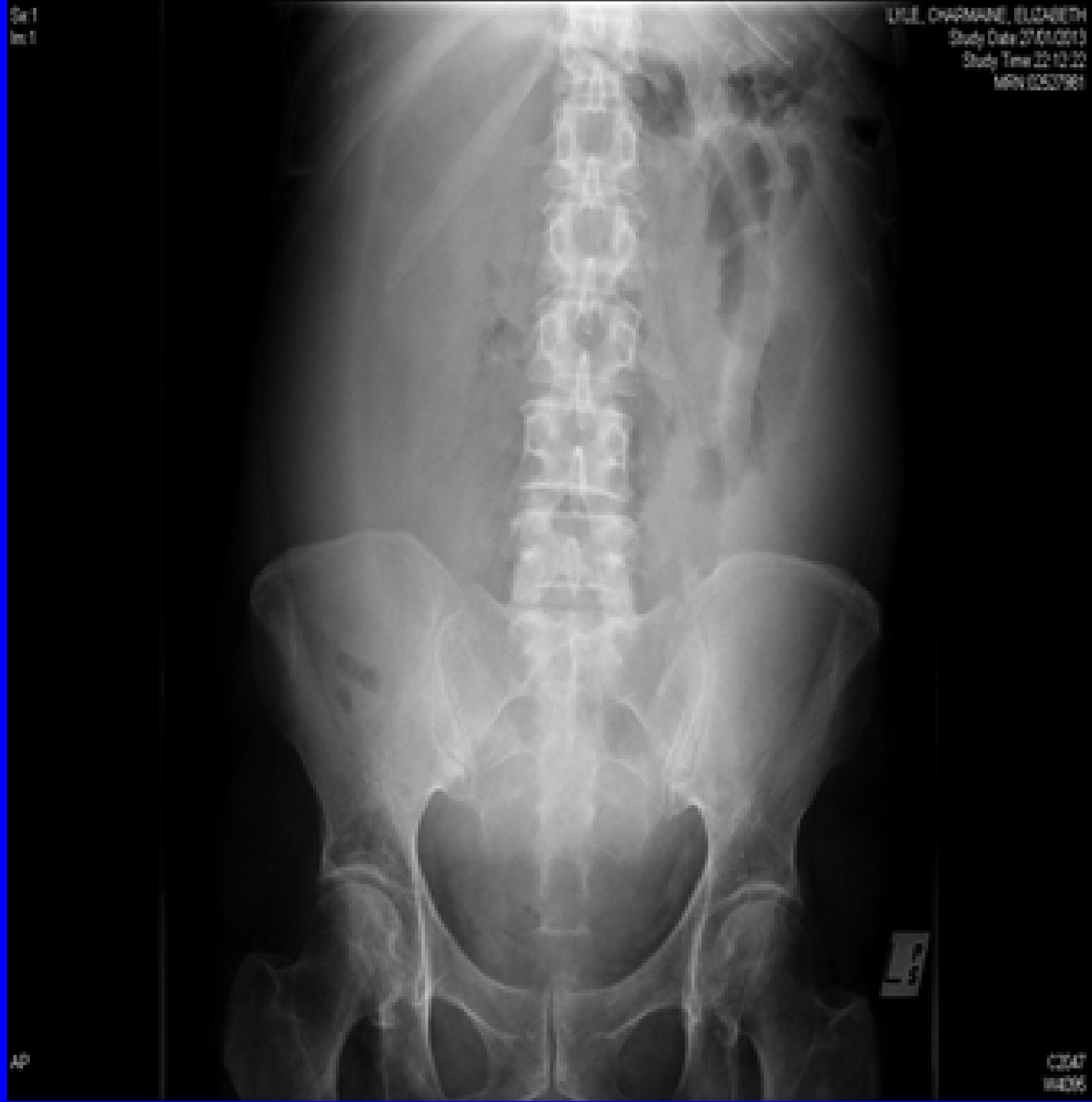
- History
- Terminology
- Incidence
- Indications
- Practice parameters
  - Guidelines/policy/framework
  - Exceptional circumstances
    - Eg: MND and NIV
    - Existential distress/ depression
- Distinguish from euthanasia

- Charmaine 60 year old
- Lawyer
- Ovarian carcinoma
  - Extensive disease
  - Complete bowel obstruction
    - Currently having chemotherapy, TPN
    - Surgical options not available
  - Hopes to return to normal diet and activity

  Past history bipolar disorder

Charmaine cont'd

- Increasing pain, vomiting, distress
- Abdominal exam
  - No bowel sounds, Distended
  - Patchy erythema on abdominal wall
- AXR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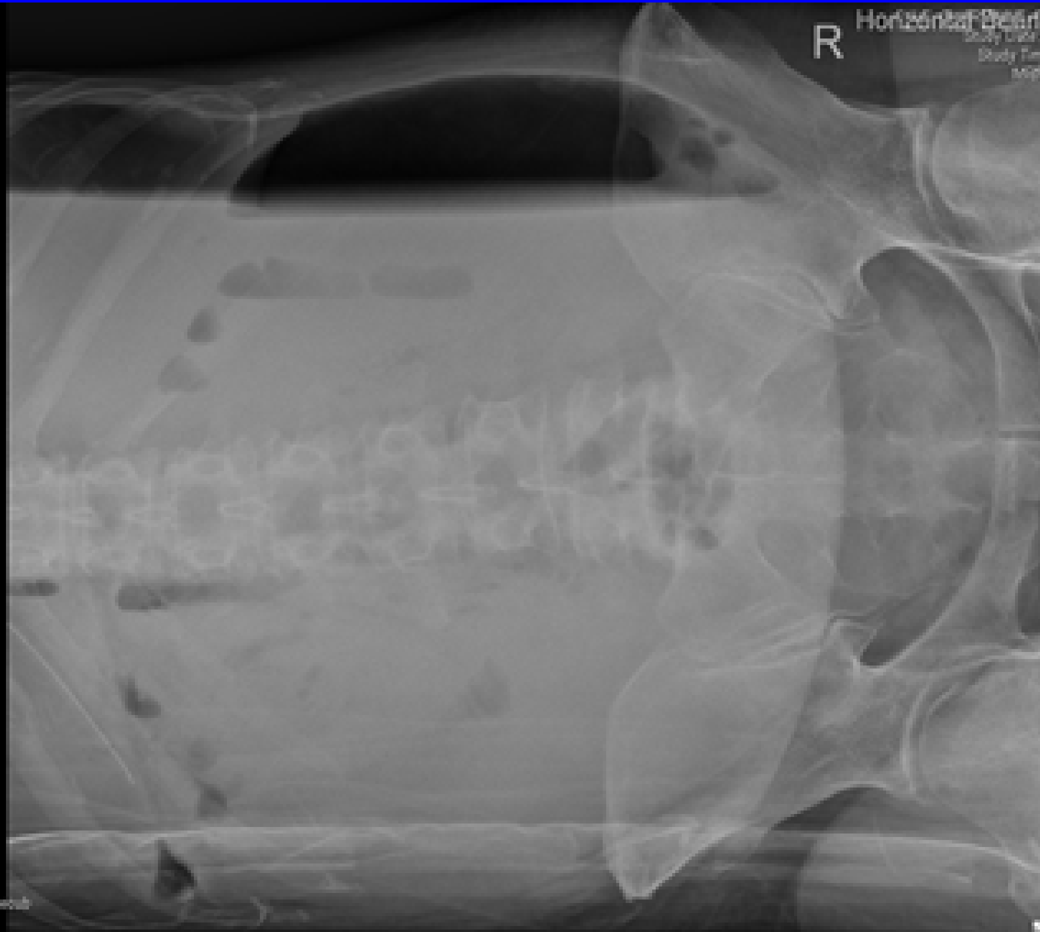


Horizontal Beam
R
Lateral Decub

- Charmaine
  - Perforated viscous
  - No surgical options
  - Discharging fistula through incision
    - Faecal discharge (litres)
  - Wants to die now
    - Pain improved
    - No vomiting
    - Slight delirium
  - Is terminal sedation appropriate?

PALLIATIVE SEDATION THERAPY

- Terminology
  - Palliative sedation
  - Terminal sedation
  - Continuous Deep Sedation until Death (CDSUD)
  - Controlled sedation
  - Ordinary sedation..Proportionate S..
  - PS until unconsciousness (Quill 2009 Ann Int Med)

- "Intentional lowering of consciousness in the last days of life,…proportional and monitored use…sedative medication…to relieve intolerable suffering,…symptom relief until natural death"

PALLIATIVE SEDATION THERAPY

- Variety of guidelines, recommendations and standards:
  - Royal Dutch Medical Assoc (KNMG) 2009
  - National Ethics Committee Veterans 2007
  - European Assoc Pall Care (EAPC) 2009
  - National Hospice Pall Care Org (NHPCO) 2010
  - Fraser Health Guidelines (Canada)
  - Calvary Bethlehem (Melbourne)
  - ANZSPM 2015?????

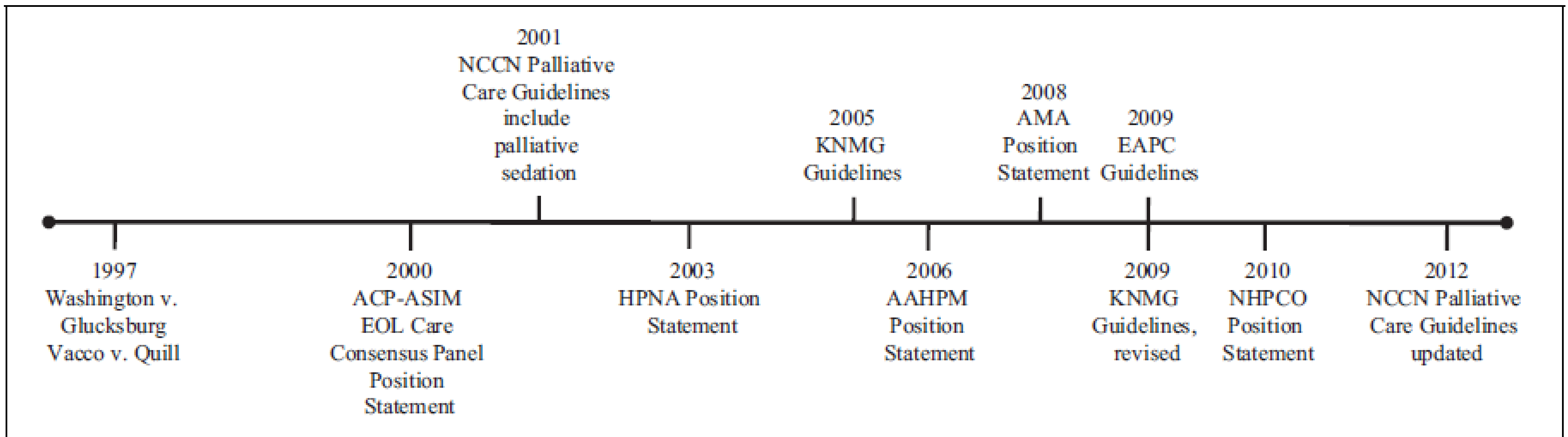


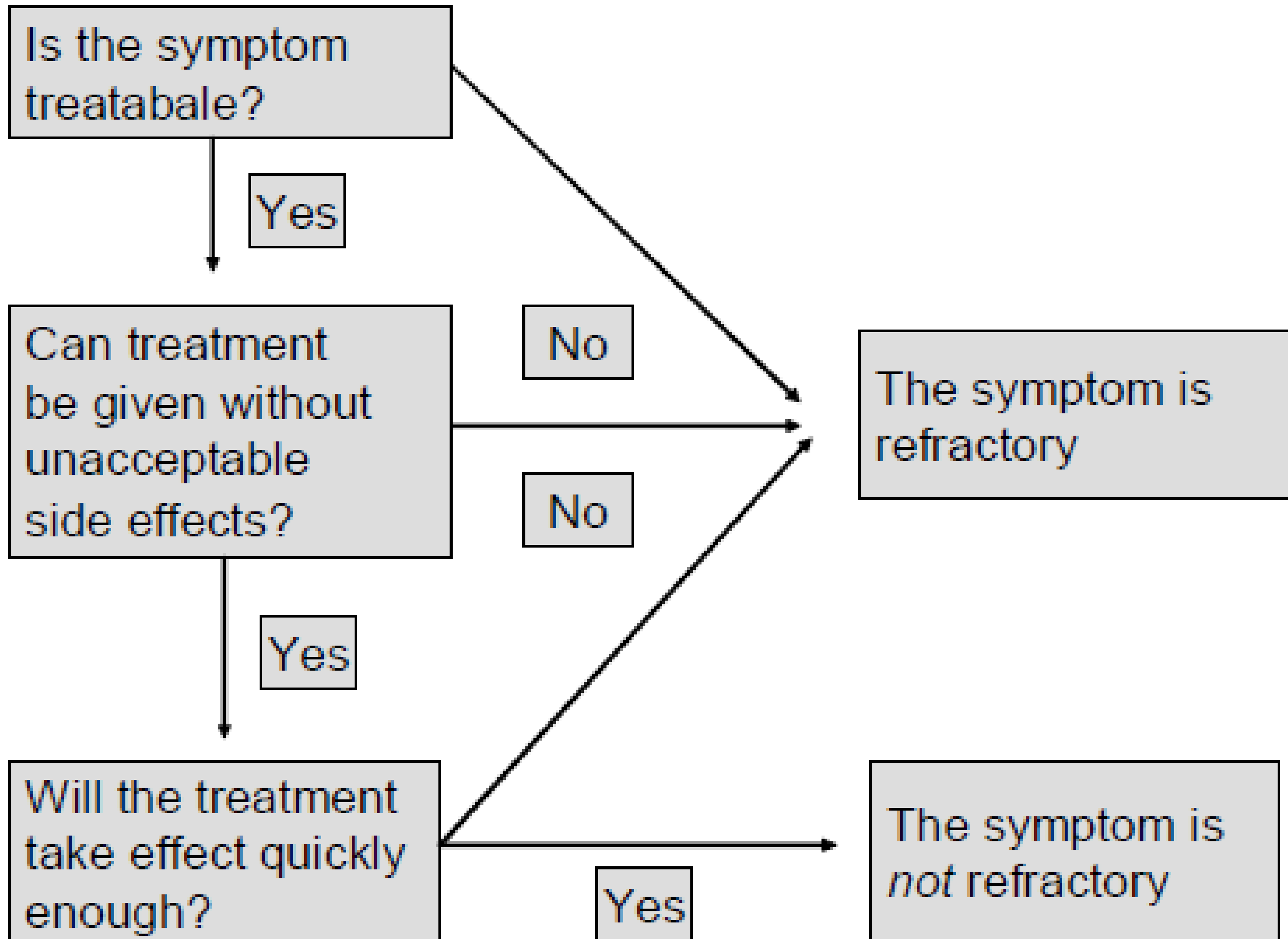
Figure 1. Time line of publications, 1997 to 2012.

REFRACTORY SYMPTOMS

- *"Symptoms for which all possible treatment has failed, or it is estimated that no methods are available for palliation within a reasonable time frame,… and a benefit:burden ratio that the patient can tolerate."* Cherny 1994
- Symptoms
  - Unbearable
  - Suffering

REFRACTORY SYMPTOMS

- Nausea, vomiting
- Dyspnoea
- Delirium
- Pain
- Existential distress


Is the symptom treatabale?
Yes
No
Can treatment be given without unacceptable side effects?
No
Yes
The symptom is refractory
Will the treatment take effect quickly enough?
Yes
The symptom is *not* refractory

SUFFERING

- Reduced well-being and QoL
- Interaction
  - Physical, psychological, spiritual, social
- "*specific state of severe distress,…events that threaten intactness of person*" Cassell 1991
- "*multi-dimensional and dynamic, …severe stress…sig threat.. Regulatory process insufficient…exhaustion*" Krikorian 2012

SUFFERING

- Assessment
  - Challenging
  - Subjective
  - Clinical interview best way to assess?
  - Tools/instruments
    - IAS (after Cassell)
    - PRISM^ (self-administered*)
    - SISC
    - Scales of suffering *
    - SOS-V

Krikorian 2013 J Pall Med

SUFFERING

- What is the effect on clinicians?
  - Feel helpless
  - Avoidance, over-identification, compassion fatigue
  - Experience of groundlessness
  - “Shaken to the core”
  - Negotiating uncertain terrain Breaden et al 2012

SUFFERING

- Clinicians experience
- Four themes
  - Fixing to being with
  - Maintaining perspective
    - Time and tempo
  - Boundaries
  - Living the Paradoxes
    - Detachment and commitment
    - Desensitisation and compassion
    - Realistic limits, yet do everything

Breaden et al 2012

PALLIATIVE SEDATION THERAPY

- Societal values changing
  - Permissivness
  - Self-determination
  - Secularisation
  - Patient autonomy, rights
- Concept first used in literature 1991
  - Enck RE. *Am J Hosp Pall Care*

PALLIATIVE SEDATION THERAPY

- Incidence
- Varies with definition
  - Netherlands 2005: 8.2% all deaths
  - Palliative care setting: 15-60%
    - 26% sedated till death Av duration 1.3 days
      - O Spruyt 1997 (London)
  - Germany (Muller-Busch BMC 2003)
    - 1995: 7%
    - 2002: 19%
  - Australia ????

PALLIATIVE SEDATION THERAPY

- Duration of PST (Verhagen (EAPC) 2005)
- < 24 hours: 47%
- 1-7 days: 47%
- 7-14 days: 4%
- > 14 days: 2%
- Supports no nutrition/hydration
  - Majority of patients short duration PST

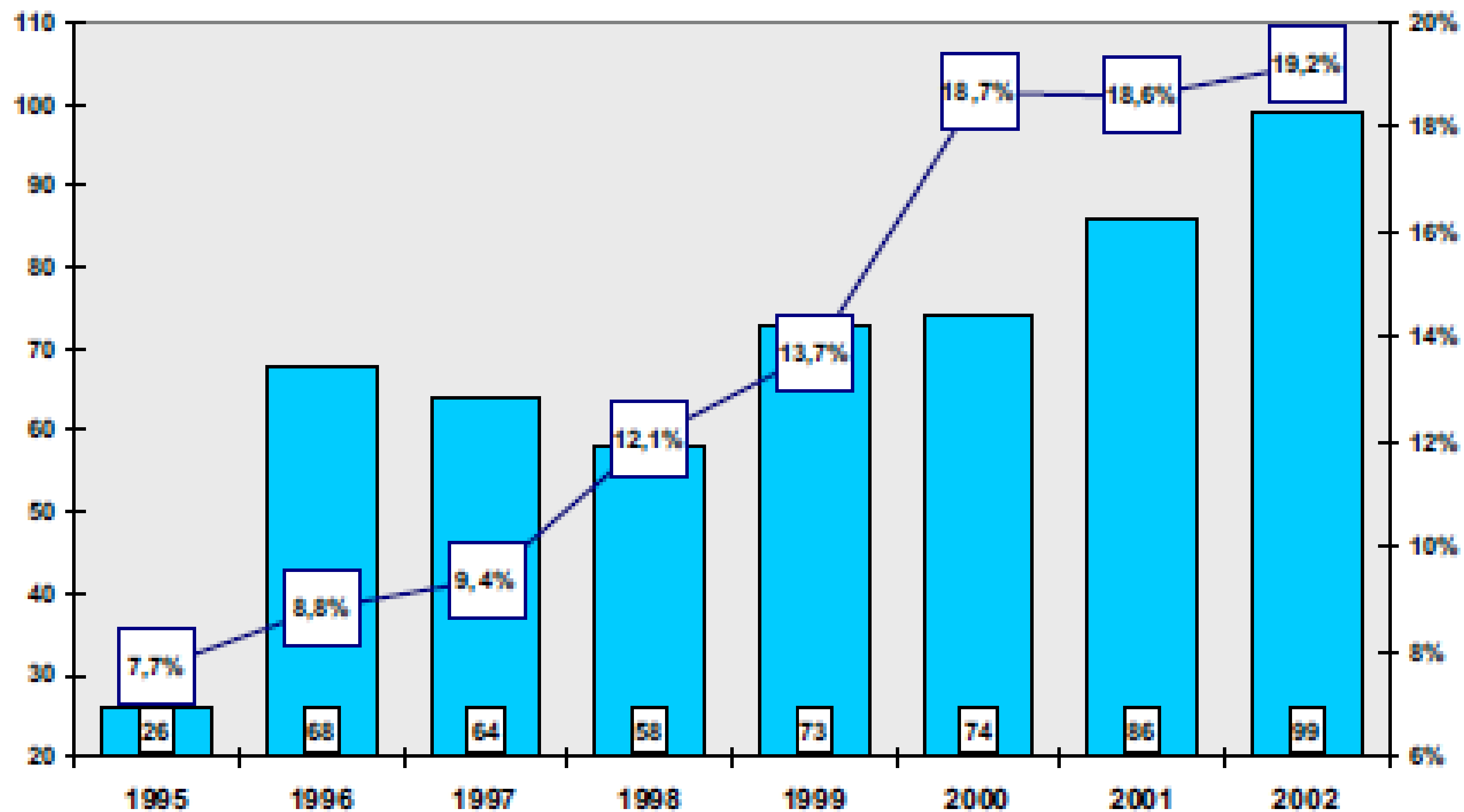
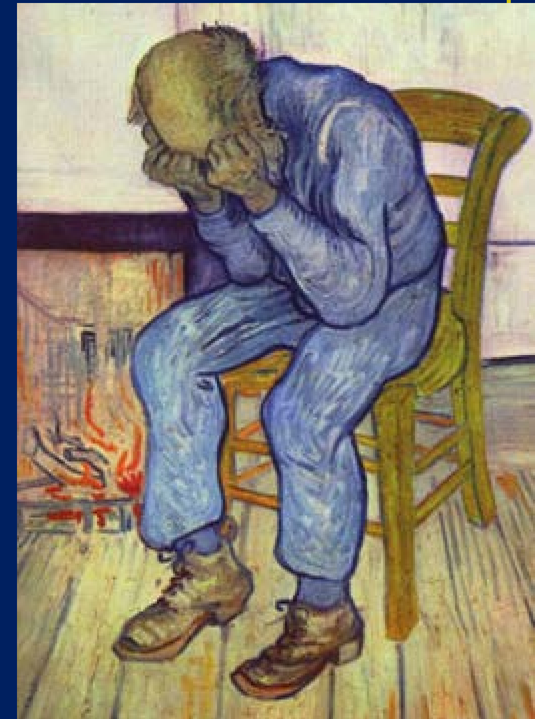


Figure 1

Percentage of patients with sedation in the last 48 hrs in relation to the number of annual deaths (bars) in care of PCU Havelhoehe between 1995 and 2002. Significant increase of incidence for sedation in the period 2000–2002 ($p = 0.015$ in paired t-test)

EXISTENTIAL DISTRESS

- Difficult to define
  - Hoplessness, meaningless, loss of self, isolation
  - Different to suffering
- Requires psychiatric involvement
  - DDx: depression, delirium, anxiety
- Emotionally charged
  - Severity dynamic , idiosyncratic, fluctuating
  - Psychological adaptation and coping evolve
- Death is not imminent
- Minimal treatment S/E
- Role of respite sedation?? Schumnan-Olivier 2008, Anquinet 2014



PST VERSUS EUTHANASIA

- "What is PS and what is *not* PS, ..euthanasia"
  - Intention
    - Not to kill but relieve Sx
  - Act (intervention)
    - Use of drugs to safely achieve sedation
  - Outcome
    - Death at some point after relief of Sx
    - "Immediate death would be an adverse outcome"

Ten Have JPSM 2014

PALLIATIVE SEDATION THERAPY CONCERNS

- Poor EBM/no RCT/guidelines all consensus
- Practice variation
  - Striking differences in prevalence
    - 1%-88%
    - ? How many receive deep PS
      - 25% PS, with only ¼ CDS (Maltoni 2009, 2012)
      - Variation by region, country, physician
  - "Terminological polysemy"
    - Papers use different definitions/no definition
    - Guidelines inconsistent
    - "Mission creep"
      - PST moving into GP realm

PALLIATIVE SEDATION THERAPY CONCERNS

- Refractory symptoms
  - Most common indication for request PST
- Euthanasia requests
  - Predominantly subjective sense of demise, and loss of dignity (Rietjens 2006 Arch Int Med)
- Religious factors
  - Vatican "deprivation consciousness deplorable"
- Financial arguments
  - Cheaper to use PST than 1:1 nursing, family

- Kerry 48 year female, divorced, 4 children
- Mesothelioma, Peritoneal disease
  - Pain
  - Intractable vomiting
  - Fatigue
- Is terminal sedation appropriate?
  - How to approach this?
  - Slow Euthanasia?
  - What to expect?
  - What to use?

- Joan 67 year female
- GBM, progressive symptoms
- “I never want to be paralysed”
- Complex psychiatric history
  - Anxiety, Depression
- Cerebral bleed
  - Right hemiplegia
  - Dysphasia
  - Dysphagia
  - Distress++++
- Is sedation for existential distress appropriate?

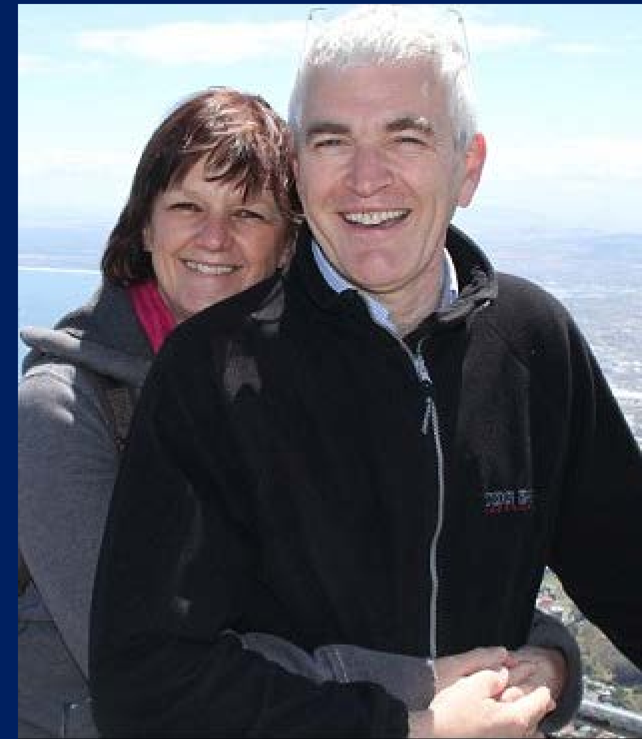
- Ron 68 year old male
- Stage 4 NSCLC, Severe COPD
- Dyspnoea, Fatigue, Cachexia
    - SR Morphine 30 mg BD
- Left pleural effusion
- AKPS 50
- Fears suffocation
- Requests to be asleep
- “Knows he is dying”

The human face of MND and Bi-level

- Mr T.; Divorced
- 64 years age,
- diagnosed with MND 2004,

2006, commenced Bi-level

- Lower limb weakness, bilateral dexterity loss, slurred speech, occasional choking, headaches on waking,
- **PC02 51, Pa02 72**
- Supportive carer but **also deaf**



Mr Isaac is the latest in a long line of terminally ill patients who have demanded for the right to end their lives

2010 to 2011

- Urgent equipment calls continue
- Zero mask free time.
- Limited or no oral hygiene…… fetid breath.
- Minimal communication from patient, carer deaf.
- Mask abrasion to nose.
- "Locked in"
  - Communicates with finger on alphabet board

- **July 2011 patient carries out Advanced Directive at home**
- **Palliative sedation**
  - **Appropriate?**
  - **How to undertake?**

PALLIATIVE SEDATION GUIDELINES SOUTHERN ADELAIDE PALLIATIVE SERVICES

- Framework/Clinical Guideline
- 6 Sections
  - Are the symptoms refractory?
  - Are the symptoms causing severe distress?
  - Criteria for initiating PST
  - Initiating and maintaining PST
  - Monitoring PST
  - Bereavement and debriefing

REFRACTORY SYMPTOMS

- Unable to control Sx
- Treatment have significant S/E
- Timeframe for relief not tolerable
    - Critical evaluation of patient
    - MDT input
    - Other specialties consulted

Is the symptom treatable?

NB: All available reasonable pharmacological and non-pharmacological options (including psychological/psychosocial interventions) should be considered

Yes

No

Can treatment be given without unacceptable side effects?

Yes

No

Will the intervention take effect within a reasonable time frame?

No

Yes

The symptom is now considered refractory

The symptom is considered manageable

DRAFT

Figure 1. Is the symptom refractory?

DISTRESSING SYMPTOMS

- Patient assessment, understanding, meaning
- Family involvement
- MDT involved
  - Patients experience of illness
  - Patient as a person
  - Disease trajectory
  - Anticipated effects PST
    - Possible S/E, loss of communication, no ANH

CRITERIA FOR PST

- Initiating PST an extraordinary intervention
- Requires series of conversations
  - Not an emergency (usually; Nb exceptions)
- Criteria
  - Life limiting illness
  - Short prognosis
  - Proportionate sedation
  - Patient (family) informed
    - Consent

INITIATING, MAINTAINING PST

- Family involved, present
- Medications
- Frequent communication for family
    - Updates, feedback
    - warning death approaching
- Meticulous nursing care
- Monitor for symptom relief

MEDICATIONS

- Continue analgesics
- Loading dose, then maintenance, adjustment
- Midazoloam
  - LD 5-10mg; CSCI: 30-60mg/24 hours
- Levomepromazine
  - LD 12.5-25mg; CSCI: 50-300mg/24 hours
- Phenobarbitone
  - LD 100-200mg; CSCI: 600-1200mg/24 hours
- Propofol
  - LD 5 mcg/kg/min; CSCI: 5-50 mcg/kg/min

MONITOR SEDATION

- Symptom relief
  - BT analgesia
  - “Relief of suffering”
- Depth of sedation
  - Richmond Agitation Sedation Score
  - BT sedation as required
- No routine observation in the dying patient
  - No BP, HR, oximetry
  - Different if intermittent sedation
    - Need equipment for airway management etc

Appendix II: Richmond Agitation Sedation Score (RASS)

Term	Score	Description
+4	Combative	Overly combative or violent. Immediate danger to staff
+3	Very agitated	Pulls/removes tubes or catheters. Has aggressive behaviour toward staff
+2	Agitated	Frequent non-purposeful movement.
+1	Restless	Anxious or apprehensive but movements not aggressive or vigorous
0	Alert and calm	
-1	Drowsy	Not fully alert, but has sustained (>10 sec) awakening with eye contact to voice
-2	Light sedation	Briefly (<10 sec) awakens with eye contact to voice
-3	Moderate sedation	Any movement (but no eye contact) to voice
-4	Deep sedation	No response to voice, but any movement to physical stimulation
-5	Unrousable	No response to voice or physical stimulation

[illegible]	Restless	Anxious or apprehensiv
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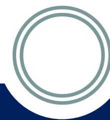

Procedure for RASS Assessment

Step	Procedure	
1	Observe patient	Patient is alert, restless, or agitated
2	If not alert, state patient's name and say to open eyes and look at speaker.	Patient awakens with sustained eye opening and eye contact
		Patient awakens with eye opening and eye contact, but not sustained
		Patient has any movement in response to voice but no eye contact
3	If patient does not respond to voice, physically stimulate patient by shaking shoulder and/or rubbing sternum*	Patient has any movement to physical stimulation
		Patient has no response to any stimulation

DRAFT

BEREAVEMENT, DEBRIEFING

- Bereavement
  - Early referral all families
  - Review with the team if required
- Care of the staff
  - May be very distressing to staff
  - Team meeting, debrief
  - Professional care
  - Time off
- Audit of all cases PST

PST AND HOSPICE PHILOSOPHY

- Changing landscape?
  - Limited and restricted use to widespread
  - Loss of connectedness, community, inclusion
  - Dying in silence
    - Patients sleeping not communicating
    - PST fails to address complexity of human suffering
  - PST the successor to “Bromptons cocktail”
    - Morphine, cocaine, ETOH, chloroform water
    - Used until the late 1970’s
    - Saunders enthusiastically embraced

SUMMARY

- PST does not hasten death (Maltoni 2012)
- PST does not replace skilled palliative care
- PST requires multi-step pathway
  - Protect the patient
  - Protect the clinician
  - Protect the institution
- Guideline/framework provides confidence
  - Clear distinction from euthanasia
    - Distinction is dissipating
    - Meaning/terminology and concept of intent
    - "Mission creep", focus on therapy not care
- Document, document, document