Overview

1. What is palliative care?
2. How does psychiatry fit in with palliative care?
3. Examples of common clinical problems
4. Management approaches
Part 1

What is palliative care?
“The Doctor” Sir Luke Fildes 1891
Modern hospice movement

Dame Cecily Saunders (1918-2005)

St. Christopher’s Hospice
Palliative care

- **Etymology:** L. *palliare* - to cloak

- **WHO definition:**

  “An *approach* that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”
Palliative care (WHO):
- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
Key ideas:

- Goals are relief of suffering & optimising quality of life
- Early involvement
- Holistic
- Individual- & System-focussed
Figure 2. The Older “Transition” Model of Care Versus a “Trajectory” Model

Palliative care approach

- Early involvement in life-limiting illnesses
- Broadening clinical scope
  - Oncological
  - Neurological
  - Cardiac
  - Respiratory
  - Renal
  - HIV
  - Multi-morbidity
  - Dementias
- Holistic
  - Patient & family
  - Bio-psycho-socio-spiritual
- Interdisciplinary
Figure 3. Chronic Illness in the Elderly Typically Follows Three Trajectories

The responsive models of interaction between primary generalist, other specialist palliative care providers, illustrate the involvement of, and linkages between, all providers of care to meet the changing needs of patients, their families and carers.

Palliative Care Australia. Strategic plan 2008-2011
Interdisciplinary team

- Staff members vary greatly depending on team
  - Palliative care physicians & trainees
  - Palliative care nurses
  - District nurses
  - Social workers
  - Bereavement counsellors
  - Physiotherapists
  - Occupational therapists
  - Pharmacists
  - Chaplains & pastoral care workers
  - Volunteers
  - Psychologists
  - Psychiatrists
Current involvement of psychiatry

- Hospital consultation-liaison service
- Private sector
- Funded positions within palliative care teams
- Psychiatrists practising dual roles in psychiatry & palliative medicine
- Research
How does psychiatry fit in with palliative care?
Why psychiatry?

- Inherent affinity between psychiatry and palliative care
  - Holistic
  - Experiential focus
  - Individual and system foci
  - Abstract, “grey” areas
  - Emotive subject matters
  - Ethical considerations
  - Art and science combined
  - Context heavy
  - Integration of biopsychosocial frameworks
  - Non-curative

- Clinical need
  - Psychiatric/psychological problems are prevalent
  - Service gaps

- Research need
  - Relatively unexplored territory
Psychiatry pioneers in palliative care

- Elizabeth Kübler-Ross
- Avery D. Weisman
- John Hinton
- Colin Murray Parkes
- Peter Maguire
- Jimmie Holland
- Harvey Max Chochinov
- William Breitbart

........etc etc.
What can psychiatry offer?

- Consultation & shared care
  - Patient
  - Bereavement

- Liaison
  - Education
  - Case discussions
  - Attending to dynamic processes
  - Team support & staff care
  - Between mental health & palliative care services

- Service development
  - Guidelines
  - Clinical programme and service development

- Research
Clinical scope

- Common problems
  - Depressive symptoms
  - Anxiety symptoms
  - Relational problems, personality styles
  - Psychological issues in the context of death & dying
  - Mental capacity
  - Intractable delirium & other neuropsychiatric manifestations
  - Psychosis
  - Complicated bereavement
  - Team issues
  - Psychopharmacology use, e.g. palliative sedation
  - Substance use disorders

- Others
  - Desire for hastened death, suicidal, euthanasia
  - Patients with severe, persisting mental illness
Barriers to successful collaboration

- Philosophical differences
  - Mainstream psychiatry focus on mental illness
  - Palliative care focus on symptoms & suffering
    ⇒ Different thresholds of clinical significance
    ⇒ “Clinical service gap”

- Unfamiliarity
  - Psychiatry with EOL issues
  - Palliative care with mental health issues & psychiatric practice

- Access
  - Unclear referral pathways
  - Practical obstacles
    - Limited hospital resources
    - Waiting time
    - Housebound/bed-bound patients
    - Small numbers of palliative care psychiatrists/psycho-oncologists

- Stigma & taboos
Examples of common clinical problems
Grief

- Response to loss
- A process of adaptation to change
- Does not occur in stages, is not linear or time-prescribed
- Highly individual
  - What is lost (usually multiple things)
  - Circumstances of loss
  - Characterological factors
  - Prior experiences
  - Current circumstances
  - Cultural factors
Plethora of models of grief

Early models
- Theoretically-derived, e.g. psychoanalytic
- Goal is detachment from the object
- Generally encompass initial phase of disbelief, intermediate phase(s) of disorganisation, then reinstitution

Empirically-derived models
- Phases are fluid, over-lapping
- Tasks of the bereft (Worden)
  1. Accept reality of the loss
  2. Work through pain of grief
  3. Adjust to a world without the deceased
  4. Emotionally relocate the deceased
- Continuing bonds
- Dual process model
- Transformation theories

Ken Doka – grieving styles
- Intuitive
- Instrumental
- Blended
- Dissonant
- Disenfranchised
- Complicated grief
  - Encompasses many forms
    - Prolonged
    - Absent/delayed
    - Psychotic
    - Extreme distress
    - Suicidality

- Risk factors:
  - Identity-defining relationship with the deceased
  - Ambivalent relationship with the deceased
  - Prior history of mood or anxiety disorder
  - Certain circumstances of death (e.g. violent, untimely, unexpected, death of a child)
- Majority of bereaved do not require professional involvement

- Some may benefit from grief counselling
  - Supportive & expressive functions
  - Containment
  - Practical guidance
  - Permission to live

- Fewer require psychotherapy

- Limited role of pharmacotherapy
  - Mainly symptomatic e.g. short-term sleep
Depression

- One of the most common clinical problem
- Broad usage of the term, clinically & in research
  - Miscommunication is common
  - Unclear prevalence (Major Depression ~15% ?)
  - Unclear evidence base for treatment
Diagnostic difficulties
- Rich context
  - Progression of life-limiting illness, declining physical functioning, multiple medications, psychological aspects of dying, existential concerns

- Limited usefulness of major depression as a concept
  - Validity in the EOL setting?
  - Different approaches
    - Inclusion
    - Exclusion
    - Substitution

- Are adjustment disorders appropriate in this context?
  - What is a “normal” reaction to dying?
### Endicott’s substitution criteria

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<thead>
<tr>
<th>DSM-IV-TR</th>
<th>Endicott’s substitution</th>
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<tbody>
<tr>
<td>Depressed mood</td>
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<td>Markedly diminished interest or pleasure</td>
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<td>Appetite or weight change</td>
<td>Tearfulness and depressed appearance</td>
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<td>Insomnia or hypersomnia</td>
<td>Social withdrawal and decreased talkativeness</td>
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<td>Psychomotor retardation or agitation</td>
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<td>Fatigue or loss of energy</td>
<td>Brooding, self-pity and pessimism</td>
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<td>Feelings of worthlessness or excessive guilt</td>
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<td>Diminished concentration or indecisiveness</td>
<td>Lack of reactivity</td>
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<td>Recurrent thoughts of death or suicidality</td>
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Recommendations

- Explore & interpret symptoms in their context (as in any other settings)
  - Context of
    - Dying
    - Life-limiting illness
    - Medications used
    - The person’s background, expectations and circumstances
  - Assess pervasiveness
  - Longitudinal assessment
  - Be specific about language use
    - E.g. “Feeling depressed” vs. “Being depressed” or having a “depressive disorder”
  - Diagnostic terminology does not translate into management plans
    - E.g. Major depression ≠ Antidepressants
    - Lack of a diagnosis ≠ no intervention
    - Formulation more useful
Management options broadly similar to other settings (for depressive disorder) with some differences

- Pharmacotherapy
  - Antidepressants
  - Psychostimulants
  - Symptomatic e.g. BZs, low-dose tranquillisers
- ECT
- Supportive care
- Psychotherapy
  - CBT, mindfulness-based CBT, ACT
  - Supportive-expressive psychotherapy
  - Narrative therapy
  - Hypnotherapy
ECT

Psychotropics (antidepressants, psychostimulants)

Psychotherapy (flexible: CBT & related approaches, psychodynamic, existential)

 Emotional & practical support (expressive, preparations for death, life review, supporting family)

Optimise control of pain & other symptoms
Demoralisation

- Introduced by George Engel
- Developed by Jerome Frank in the psychotherapy context (1970s)

**Demoralization: its phenomenology and importance**

David M. Clarke, David W. Kissane

**Objective:** Demoralization, as described by Jerome Frank, is experienced as a persistent inability to cope, together with associated feelings of helplessness, hopelessness, meaninglessness, subjective incompetence and diminished self-esteem. It is arguably the main reason people seek psychiatric treatment, yet it is a concept largely ignored in psychiatry. The aim here is to review and summarize the literature pertaining to demoralization in order to examine the validity of the construct.

**Method:** A narrative review of demoralization and the related concepts of hope, hopelessness, and meaning is presented, drawing on a range of empirical and observational studies in the medical and psychiatric literature.

**Results:** An examination of the concepts of the ‘Giving Up–Given Up’ syndrome (George Engel), ‘suffering’ (Eric Cassell), and demoralization (Jerome Frank), demonstrate considerable convergence of ideas. Demoralization has been commonly observed in the medically and psychically ill and is experienced as existential despair, hopelessness, helplessness, and loss of meaning and purpose in life. Although sharing symptoms of distress, demoralization is distinguished from depression by subjective incompetence in the former and anhedonia in the latter. Demoralization can occur in people who are depressed, cancer patients who are not depressed and those with schizophrenia. Hopelessness, the hallmark of demoralization, is associated with poor outcomes in physical and psychiatric illness, and importantly, with suicidal ideation and the wish to die.

**Conclusions:** Demoralization is an important construct with established descriptive and predictive validity. A place needs to be found for it in psychiatric nomenclature.

**Key words:** adjustment disorder, classification, demoralization, depression, primary health care.

*Australian and New Zealand Journal of Psychiatry 2002; 36:733–742*
Features of demoralisation (Clarke & Kissane):
- Subjective incompetence (inability to cope, sense of personal failure)
- Distress
  - Helplessness
  - Hopelessness
  - Meaninglessness
- Isolation

Spectrum
- Disheartenment → existential despair & suicide
Conceptual overlap with depression & grief, but not the same

- Demoralisation – subjective incompetence, helpless, hopeless
- Depression – loss of interest, anhedonia
- Grief – yearning for lost object
- Much more common than depressive illness

- Associated with:
  - Personal factors
    - Younger age
    - Poor self-esteem
    - Avoidance & resignation as coping strategies
  - Illness factors
    - Severe and progressive illness
    - “Bad news”
    - Disfigurement
    - Serious mental illness
    - Poor symptom management
    - Prominent side effects of cancer treatments
  - Social factors
    - Social isolation & poor family cohesiveness
    - Cumulative losses
Clinical implications

Management

Symptomatic relief

Psychotherapeutic approach

Cognitive strategies (information, reality testing, problem-solving, cognitive distortions, explore meanings)

Behavioural strategies (goal setting, activity scheduling, restore sense of mastery, re-engagement in relationships)

Supportive-expressive dynamic strategies ("being with", empathic understanding, exploration and insight building, meaning and spirituality)

Impact on decision-making

Impact on clinicians

Therapeutic despondency/nihilism

Euthanasia or physician-assisted suicide
Part 4

Management approaches
7 general points:

#1 Flexibility

- **Assessment**
  - Often can’t take a full history
  - Repeated assessments
  - Timely response to referrals
  - Home visits

- **Treatment**
  - Approaches
    - Eclectic
    - Fluid
  - Goals constantly shifting
  - Creative and opportunistic interventions
  - Routes of administration of drugs
#2 Timeframe

- Limited timeframes for intervention
- Unpredictability

⇒ Be realistic, you can’t solve everything
⇒ But this should not be an excuse for not intervening at all
#3 Altered pharmacokinetics & drug interactions

- Patients often on:
  - Combination analgesics, including opiates
  - Dexamethasone
  - Ketamine
  - Benzodiazepines

- Multiple diseased organs
  - Sensitivity to drug effects
  - Impaired drug clearance
#4 It’s not always about death

- Issues at hand may have little to do with illness & dying, e.g. financial problems, marital dysharmony

- Underlying life problems may come to a head during illness and at the EOL

- Not everyone needs to discuss the meaning of life or death and dying

- Meaning can be derived from mundane things
#5 Psychotherapeutic issues

- Take a considered approach:
  - Protecting fragility (bolstering defence mechanisms rather than challenge them)
  - Anticipation of problems

- Common themes:
  - Meaning of illness (often perceived retribution)
  - Guilt
  - Meaning of life
  - Identity
  - Isolation & detachment from others
  - Leaving loved ones
  - Death anxiety
  - Trauma/torture
#6 Watch out for therapeutic nihilism or despondency

- **Patient factors**
  - Depression, demoralisation
  - Coping difficulties
  - Complex social problems

- **Illness factors**
  - Horrific disease or complications
  - Co-morbidities

- **Doctor factors**
  - Fears, e.g. own death anxiety, fear of failure, loss of control
  - Previous experiences of death & dying
  - Dynamic changes in state of mind
#7 Self-care

- Nature of work
  - Burnout, compassion fatigue
  - Grief
  - Vicarious trauma
  - Helplessness

- Own psychological characteristics
  - Importance of team work & support
  - Supervision & peer groups
  - Self-reflection
  - Balanced life
Existential Psychotherapy

- Existentialism
  - Philosophical movement arising in mid-19th century
  - Central concerns are the human condition - subjective experience of being human and meaning of life

- Existential psychotherapy
  - Uses existential philosophical frameworks
  - Various forms and proponents
Victor Frankl

- Logotherapy
  - “Will to meaning” as the primary motivational force in man
  - All situations have meaning
  - 3 categories of meaning pathways:
    1) Creativity
    2) Experience
    3) Attitude
Irvin Yalom

“Humans are the only creatures for whom our own existence is the problem”

- A dynamic approach to therapy which focuses on concerns that are rooted in the individual’s existence

- 4 “ultimate concerns of life”:
  1) Death
  2) Freedom
     - Responsibility
     - Will
  3) Existential isolation
  4) Meaninglessness

- Boundary experiences
Dignity therapy

- Dignity – “the quality or state of being worthy, honoured or esteemed”

- Empirical Dignity Model

**Chochinov’s Dignity Therapy**

A form of manualised, time-limited therapy, focussing on life narrative, with the production of a “generativity document” as a result of the process.

<table>
<thead>
<tr>
<th>Dignity Therapy questions</th>
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<tbody>
<tr>
<td>Can you tell me a little about your life history, particularly those parts that you either remember most or think are the most important?</td>
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<tr>
<td>When did you feel most alive?</td>
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<tr>
<td>Are there specific things that you would want your family to know about you, and are there things you would want them to remember?</td>
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<tr>
<td>What are the most important roles you have played in life? Why are they so important to you and what do you think you accomplished in those roles?</td>
</tr>
<tr>
<td>What are your most important accomplishments and what do you feel most proud of?</td>
</tr>
<tr>
<td>Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?</td>
</tr>
<tr>
<td>What are your hopes and dreams for your loved ones?</td>
</tr>
<tr>
<td>What have you learnt about life that you would want to pass along to others?</td>
</tr>
<tr>
<td>What advice or words of guidance would you wish to pass along to your ___?</td>
</tr>
<tr>
<td>Are there words or perhaps even instructions you would like to offer your family, in order to provide them with comfort or solace?</td>
</tr>
<tr>
<td>Are there other things that you would like to include?</td>
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Last words

- Palliative care psychiatry is psychiatry
  - Broad spectrum of clinical issues
    - Psychological
    - Existential
    - Neuropsychiatric syndromes
    - Systemic
  - Fertile grounds for developing therapeutic skills

- Rewards
  - Privileged position
  - Team work
  - Humanistic learnings
  - Meaningful