



Dying and palliative care

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Overview

- Working with the dying
 - Practical aspects – role of psychologists in palliative care
 - Mental health in palliative care - the big 3
 - Therapeutic relationship & talking about dying
- Facing mortality
 - How does the work affect US?
- Discussion

“If they’re dying they’re about to lose everything:
relationships, home, dignity, health, favourite books,
Sunday sleep-ins, beach holidays, wine, long walks, friends,
going out to dinner, building cubbies, kisses, overseas trips,
barbecued sausages, assets, reading bedtime stories,
birthdays, all-time favourite albums, children laughing, the
smell of mown grass, breathing sea air, dodging rain
showers, sunrises and sunsets, wind in their hair, coffee
brewing, music and poetry,
EVERYTHING.

Expect them to be a bit grumpy from time to time”

The palliative phase...

- Transition to palliative care - highly emotional time for patients and their loved ones
- Palliative stage of treatment - often already endured a number of difficult experiences
 - investigations - (invasive)
 - therapies
 - pain, nausea, appetite disturbance, sleep problems
 - progressive disease and reduced function
- Sudden diagnosis of terminal illness - shock, disbelief, denial, distress, adjustment

Impact - Identity & other considerations



Body image & sexuality

- Body image - hair loss, oedema, scarring, stoma, weight changes
- Sexuality - loss of sexual function - decreased libido, pain, atrophy, withdrawal due to fatigue, illness, or perceived unattractiveness



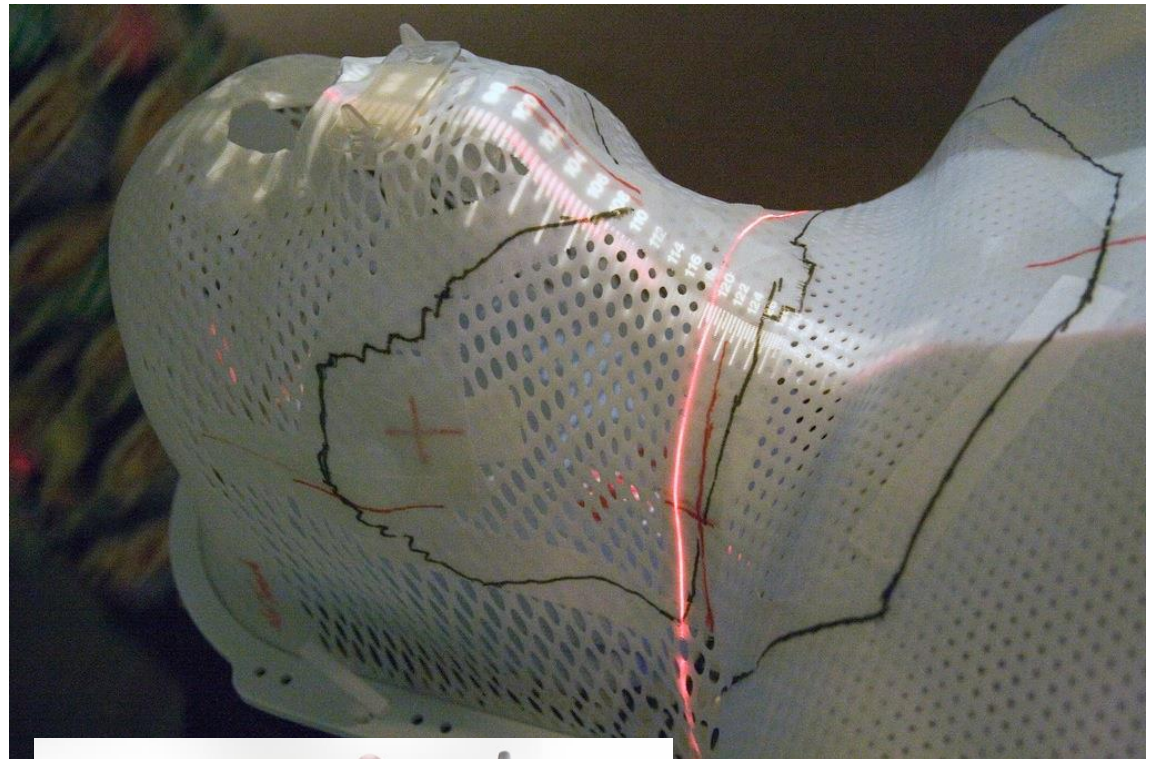
Relationship and role changes

- Relationship dynamics shift - partner-partner to patient-carer
- Role changes - unable to perform usual role functions



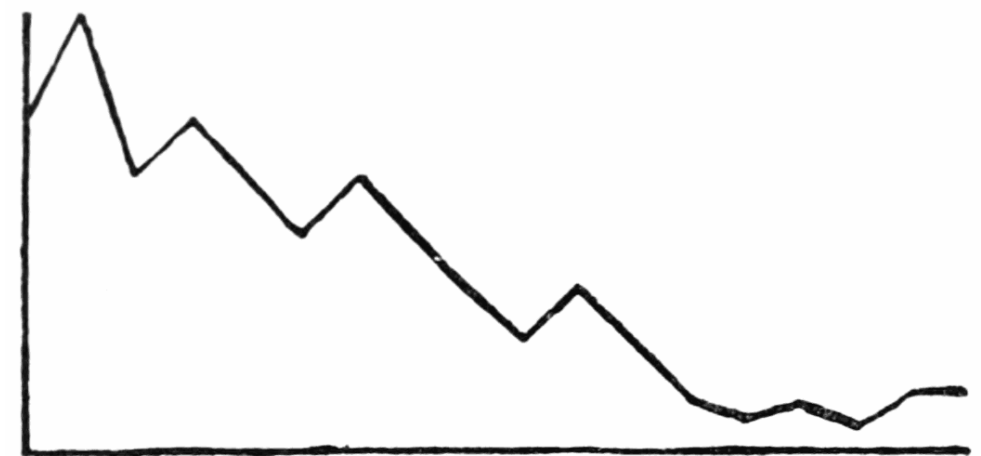
Coping with treatments, financial, legal concerns

- Treatments - uncertainty about efficacy; frightening procedures
- Financial changes as result of loss of functioning
- Legal - wills, custody



Nature of illness & disease trajectory

- Characteristics of illness - each disease carries own issues, e.g. GBM, breast cancer, ESRF, bladder cancer, MND
- Illness trajectory - sometimes uncertain - downward slope, descending plateaus
- Malignant vs non-malignant disease



Coping with physical symptoms; cognitive changes

- Physical symptoms; pain, nausea, fatigue, low energy
- Changes in cognition; personality changes
- Capacity

Cultural understanding of illness and death

Important to ascertain one's cultural meaning ascribed to illness and death



Role of psychologists in palliative care

- Assessment
- Interventions
- Recommendations to treating team
- Staff support – debrief team, reflective practice, education, assist with complex cases, management program
- Education/Secondary Consult

Mental health in palliative populations

Psychiatric presentations in palliative care

Possible causes of mental state changes

- Advanced disease processes, e.g. brain metastases, leptomeningeal disease, paraneoplastic syndromes,
- Whole brain irradiation
- Medications or medication interactions (e.g. corticosteroids)
- Metabolic changes; e.g. thyroid function; infection (UTI, sepsis)
- Relapse of pre-existing psychiatric disorder - mood, anxiety, psychotic disorders
- Re-emergence of trauma
- Dementia
- Delirium – hyper-active and hypoactive or mixed types
- Adjustment & mental illness – depression, anxiety, demoralisation, existential concerns
- Complex/challenging family dynamics
- Expressed suicidal ideation

Management of psychiatric presentations in palliative care

Treatment is multi-faceted

- Medical investigations - CT brain scans, MRI
- Pharmaceutical – anxiolytics, antidepressants, (e.g. mirtazepine), anti-psychotics, mood stabilizers
- Psychological
- Spiritual/existential
- Art, music therapy; massage

Psychological wellbeing

- Shock, grief, anger, denial, demoralisation, anxiety, guilt, resignation, acceptance
- Loss +++



“It will happen to all of us, that at some point you get tapped on the shoulder and told, not just that the party’s over, but slightly worse: the party’s going on — but you have to leave. And it’s going on without you.” Christopher Hitchens

Depression in palliative care

DSM-V criteria include numerous somatic features such as,

- Disturbed sleep
- Increase/decrease in appetite
- Loss of energy or fatigue
- Psychomotor retardation
- Loss of motivation
- Problems with concentration and memory

ALL COMMON SYMPTOMS IN END OF LIFE

Depression in palliative care

Alternative depression criteria for terminally ill patients

Endicott (1984) Substitute Symptoms

- Depressed mood most of the day
- Markedly diminished interest or pleasure in all or almost all activities most of the day
- **Depressed appearance
- **Social withdrawal or decreased talkativeness
- **Brooding, self-pity or pessimism
- **Lack of reactivity; cannot be cheered up
- Feelings of worthlessness or excessive/inappropriate guilt
- Suicidal ideation or planning (more than a wish to die)

Depression in palliative care

- Studies indicate up to 45% of palliative patients experience major depression (Hotopf, et. al., 2002); other findings 19.3% for major depression & further 36% for any depressive syndrome (Rayner, et. al., 2010).
- Often under-diagnosed in palliative populations
 - Clinicians believe depression is appropriate/‘normal’ in advanced disease and palliative situations
 - Belief that nothing can treat distress at end of life

Anxiety

- Australian findings suggest 20%-36% of palliative patients experience anxiety to ranging degrees (O'Conner, White, Kristjanson, 2010)
- Existential anxiety; Body processes (e.g. shortness of breath); Injections/procedures; Dying process; Death itself; Leaving loved ones behind;
- Pre-existing; reactive; result from illness or treatment
- Somatisation is **COMMON** - anxiety presenting with physical symptoms e.g. pain

Delirium



Delirium

Very common in end of life care – up to 85% of terminal patients

Features

- **RAPID ONSET**
- **ALTERED STATE OF CONSCIOUSNESS**
- Attention deficit
- Restlessness (or apathetic, lethargic, withdrawn state in hypoactive delirium)
- Confusion
- STM disturbance
- Impaired thinking and judgment - **CHECK ORIENTATION TPP**
- Perceptual abnormalities – visual hallucinations/misperceptions
- Disturbed sleep wake cycle – reversal
- Affect disturbance – fearful, frightening, paranoia
- Abnormal behaviour
- Abnormal psychomotor activity – hyper or hypo active
- **FLUCTUATING COURSE**

Causes of delirium

- Medications (opioids, steroids, etc)
- Infection (UTI, sepsis)
- Metabolic disturbances – neutropenia
- Hypoxia,
- urinary/faecal retention
- Paraneoplastic syndromes
- Leptomeningeal disease
- **Sometimes reversible
- **Often multifactorial so can be difficult to determine cause

Differential diagnoses for delirium

- Dementia
- Psychosis
- Depression (hypoactive delirium frequently misdiagnosed as depression)
- Mania (this is also a risk factor for delirium)
- Terminal restlessness (a particular form of delirium)

Treatment for delirium

- Assessment – severity of delirium, safety (risk to patient), onset in light of medication changes or metabolic changes, cognitive impairment.
- Pharmaceutical treatment – Treatment reversible causes; antipsychotics can alleviate symptoms; haloperidol; olanzepine or quetiapine – levomepromazine;
- Orientation cues in persons environment– calendar, familiar photos, pattern of consistency, reduce loud noises and overstimulation
- Educate family about the delirium
- When (if) person emerges from delirium, they may be quite traumatised.

Therapeutic relationship & approaches



Therapeutic approaches

- Cognitive Behavioural Therapy
- Meaning focused therapies (Breitbart, Chochinov)
- Interpersonal psychotherapy
- Mindfulness therapies – ACT, MBCT, MBCR, MSC for cancer
- Hypnosis for pain, anxiety, symptom distress
- Brief dynamic psychotherapies
- Dignity therapy (Chochinov)
- Narrative therapy
- CALM therapy (Managing Cancer & Living Meaningfully - Rodin)
- Psilocybin assisted psychotherapy - (Griffiths; Ross; 2016)

There's a
life
behind
these
eyes



Beyond the models...

- All patients need to tell their story – in their own way
- Stay with them through pain, revulsion, heartbreak, body changes, loss of dignity – be mindful of displaying discomfort
- Back to basics – active listening; compassionate presence
- Elicit the meaning unique to that person –
 - Illness
 - Life
 - Suffering

Therapeutic relationship

- Boundaries
- Touch - may reach for your hand in vulnerable moments
- Strong counter-transference
- ‘Unofficial’ duties – fetching some water, helping to get the patient comfortable, dealing with interruptions, etc.
- Therapeutic goals are different
- Psychological Comfort is main objective
- Unfinished business
- Resistance allowed – patient sets the pace
- Family work

Difficult discussions

- Often sense impending death
- Let the individual set the tone – be flexible as focus often changes
- Questions best answered by physicians should be redirected to them.
- May need to advocate for patient

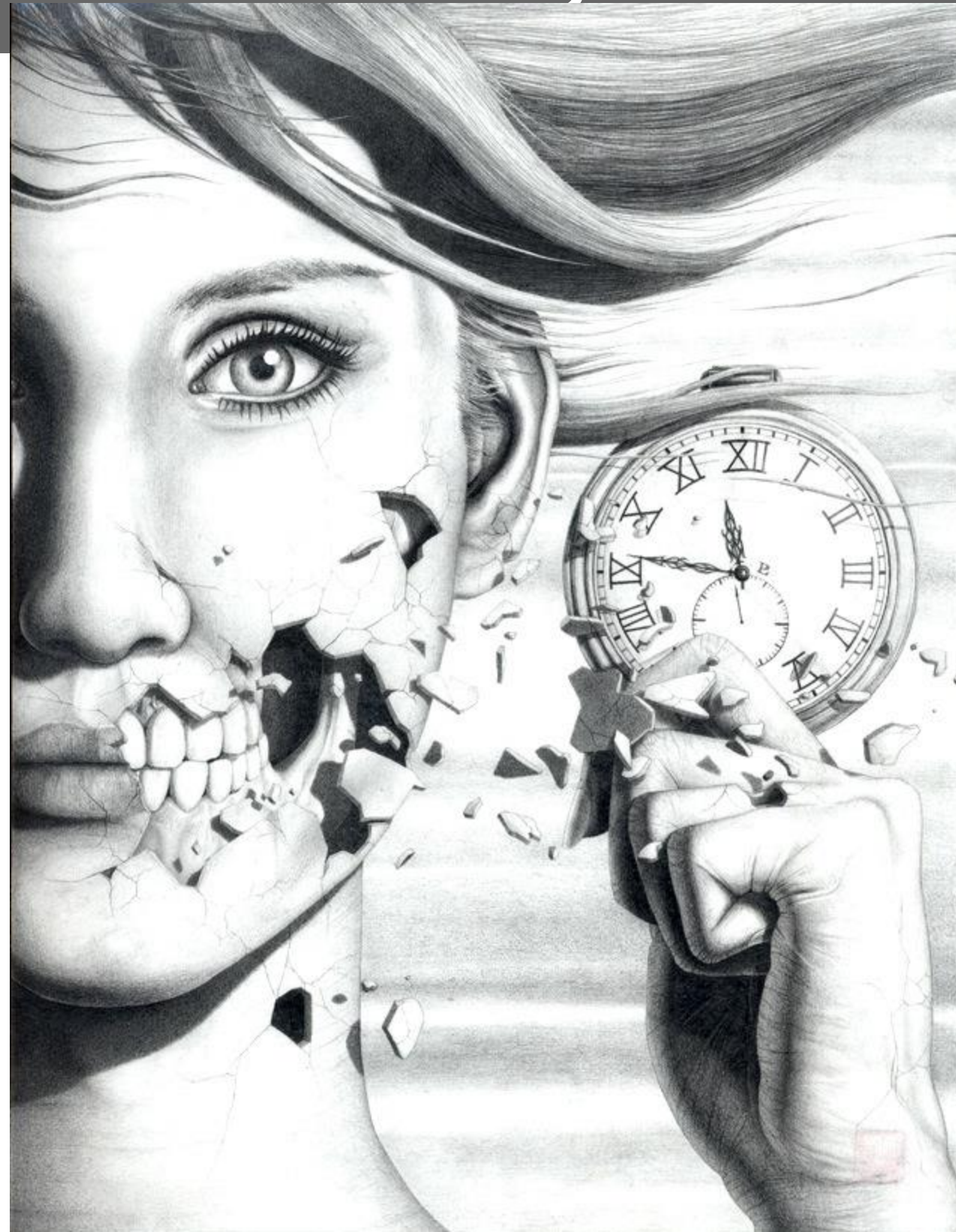
Common questions of the person with life-threatening illness

- “Am I going to die?”
- “What does dying look like?”
- “How will I know I’m dying?”
- “Will there be pain, loss of dignity, abandonment?”
- “What if (errors delays, omissions, poor management)”
- “Why?” Causes, meaning
- “What happens next?” Practical, spiritual concerns

Responding to questions of the dying person

- Responding which allows individuals to reflect.
- Can answer the question with another question:
 - “What’s your understanding of what’s happening?”
 - “Have you sensed a change?”
 - “Are you feeling scared?” “What’s the most frightening aspect?”
- Calm discussions about death anxiety and origins of such fears can alleviate distress – opportunities to discuss this are important – don’t push if patient is not wanting to discuss.
- When feeling is mobilised, allow ventilation.
- When asking about palliative care – ‘the team will aim to keep you as comfortable as possible the whole time’.

Facing mortality



Death and the therapist...

What this work requires of us

- Review our own losses
- Confronted with mortality of loved ones, ourselves
- Examine our motivations for doing this work
- Awareness of how our own issues can affect us and therapeutic relationship
- Stay with the patient in the face of very painful issues –can't 'fix' death
- Therapist - personal discomfort with dying; past experiences;
- **AWARENESS** of our own processes - over-involvement, helplessness, avoidance, etc.

Working with dying – looking after ourselves

- Supervision!
- Opportunity to debrief
- Self Care is essential – exercise, nutrition, sleep, fun.
- Be mindful of compassion fatigue and natural grief reactions during work
- Consider own therapy
- Engage in our own meaningful activities

Thank you!

Thank you!

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