Psychological Reactions: towards The End of Life

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Recall your most remembered terminal cancer patient.

What makes him/her so memorable to you?
1. Have you witnessed a terminal cancer patient suffering from pain?
2. What did you observed?
3. What were your reactions?
4. How do you describe cancer pain?
5. What have been the difficulties for you in facing cancer pain?
6. What is your attitude towards death & dying?
Pain and sufferings, 
Death & dying, 
Fears & anxieties 

It is often a mix of all three in terminal cancer patients.
Questions we need to explore:

- Patient’s *subjective experiences* (internal reality) and *social contexts*.

- Psychological reactions: to illness? to the pain? to anticipatory death? to feared loss of control? to uncertainty? to hospitalization? to the health care system? to the trust and distrust in relationships? reactions to a difficult situation?

- Whose reactions?
What is Hospital?

- Efficiency & cost-effectiveness
- Speed, time-pressured
- Noises & Interruptions
- Full of uncertainties & unpredictabilities
- Multiple people, multiple roles, multiple procedures, multiple interactions, multiple happenings… “chaotic”
- Certainly not a place to rest in peace
High tech – Low touch

- Pain and sufferings being ‘unseen’, being medicalized
- Emotions are being invalidated (diagnosed, medicalized, marginalized, isolated)
- Institutionalization of death & dying, pain & sufferings
By the time patients come to you, they probably have already gone through series of traumatizations:

- From diagnosis, “breaking bad news”, treatment failure, cancer relapse, financial difficulties, ...
- Primary and secondary traumatizations...
- Being diagnosed of cancer is an emotional experience.
- Facing end of life is emotionally and mentally draining.
Psychological reactions:

- Fear – severely life-threatening
- Imagined fears
- Anticipatory grief

- Too frightened by the word “death”
- Pain associated with fears of dying from a painful death, dying with loss of dignity, loss of independence & autonomy, fears of separation from loved ones...
- In a competitive society – being seen as “game over”, “failure”, even shame...
If environment is unstable, unpredictable, and unfavourable, other reactions include:

- Helplessness
- Loss of sense of control
- Futility
- Hopelessness
- Loneliness and isolation
- Emotional distress – depression, anxiety
- Anger & frustrations
- Exhaustions
Breaking bad news survey
(Lee et al, 2007)

- Questionnaire - anonymous return
- N=122 doctors
- 17 specialty departments
Most Difficult News to Break (N=122; multiple responses)

- Failure of a treatment: 31.1%
- Exhaustion of treatment options: 30.3%
- Dx of serious illness: 23%
- DNAR: 16.4%
- Towards end-of-life preparation: 16.4%
- Relapse: 4.9%
Toughest Part in Breaking Bad News  (N=122; multiple responses)

- pts/ relatives not emotionally accept situation: 49.2%
- handling patients/ relatives emotions: 46.7%
- engaging multiple family members: 37.7%
- requested by relative not to disclose to patient: 33.6%
- patients cannot comprehend or understand: 26.2%
- handling questions about uncertainty: 26.2%
- being totally honest: 20.5%
- feel like taking away patients' hope: 18.9%
- how much to tell: 15.6%
- opening or closing the session: 10.7%
- feel like causing emotional pain in patients: 8.2%
- handling own emotional reactions: 7.4%
- suggesting palliative care: 7.4%
- presence of relative(s): 3.3%
Most Difficult Emotions to Handle  (N=122 multiple responses)

- Anger: 57.4%
- Denial: 35.2%
- Lack of response: 23%
- Crying: 22.1%
- Out-of proportion calmness: 15.6%
- Silence: 12.3%
- Helplessness: 7.4%
- Depression: 5.7%
- Anxiety: 4.1%
- Expressed grief: 3.3%
- Fear: 0%
What do you fear most? (N=122; multiple responses)

- Being blamed for treatment failure: 49.2%
- Medico-legal consequences: 48.4%
- Overwhelmed by emotions: 27%
- Talking about treatment failure: 14.8%
- Talking about dying: 13.1%
- Talking about death: 10.7%
Psychic pain – deep sense of multiple losses & conflicts

- Internal conflicts, unspoken underlying issues, family secrets.

- The psychosomatic aspects of cancer pain
  - Symptom clusters – pain, sleeping difficulties, fatigue, poor appetite

- Pain is overwhelming & unbearable...
N=1375 palliative cancer patients (ambulatory)

Lee et al, 2011

Major source of stress – bodily pain & discomfort = 56%

- pain
- fatigue
- sleep problems
- poor appetite
- physical mobility difficulties
- breathing difficulties
- skin problems
- deteriorating memory
- constipation
- concentration difficulties
- self-care ability
- swelling
- bodily appearance
- swallowing difficulties
- digestion problems
- limb pain
- nasal problems
- vomit
- bowel habit change
- oral pain
- diarrhea
- fever
- sex
Multi-dimensionality of Pain

- Physical,
- Psychological,
- Emotional,
- Social,
- Spiritual,
- Cultural
Other factors:

- type and stage of cancer, cancer relapse
- nature of the pain, location, duration

- Patients’ perception of control
- Opportunities to ask questions and getting explanation
Risk factors
• intolerable stress (e.g. somatic distress, financial stress)
• living alone
• “nobody takes care of me”

Protective factors
• positive doctor-patient relationship
• social support
• concrete support (e.g. addressing patients’ information needs)

Lee et al 2011
N=1375 palliative cancer patients (ambulatory)
Cancer pain is not solely “something wrong inside the patients” (internal attribution)

very often it is associated with external factors – environmental causes, system issues, communication barriers.

Mostly react to the environment – the perception and interpretation of the cancer diagnosis and treatment
Defensive medicine

- Fragmentation of the medical system and flow

- Killing the patients psyche before they die – rendering them helpless & hopeless:
  - “poor communication, an apparent insensitivity to the Ss' conditions, evasion of direct questions, deliberate use of medical jargon, and an expressed unwillingness to give information, was correlated with Ss' dissatisfaction” (Phillips, 1996).
“I know better, I am a professional”

- Lack of sensitivity
- Ignore patient’s reported symptoms
- Deny treatment side effects
- “Objective reality” imposed upon patient’s subjective experiences
- Invalidations of patient’s inner reality
- Talk down to patient, shut down patients’ voice
Our privileged position:

- Middle-class health-care professional perspective
- Rationality vs emotionality
- Our own perceptual & judgment biases
Awareness

- Our assumptions, our ways of thinking
- Our ways of understanding and interpreting

- Stereotypes the patients and their reactions – gender biases, ageism, ethnicity, etc.
- Patients’ need to know
- Patients’ right to choose
- Sensitivity to patient’s experiences, psychological needs, expectations and social goals
- Getting the whole picture & the social context
Inadequate management of cancer pain

- Vulnerable groups – poor, elderly, ethnic minority, communication barriers, low education, no family support
Patients as our teacher – they teach us about life

- The real classroom is in the ward, bedside, the clinics
Healing

- build trust, listen to their personal stories and illness experiences
- understanding the social context and patient’s experience
- communicating with another human being, unique human being

- my needs & anxieties if I were the patient
Meanings & attitudes

- Meaning of the cancer diagnosis e.g. cancer growing inside your body

- Meaning of the pain – signal of underlying disease and cancer progression, a mean to stay ahead of cancer, a tool of communication with providers (need to sense/feel the pain – not take pain medication)  Meghani & Houldin (2007)
How do you explain cancer pain to patients?

Before you explain to patients, have you ever asked them the following questions:

1. What comes to your mind when you hear the words cancer pain?
2. What do you think is causing your pain?
3. What has it been like living with the pain?
4. How does the cancer pain impact on your life, your functioning, activities of daily living?
5. How do you deal with cancer pain? What helps when you are in cancer pain?

Meghani & Houldin (2007)
The high risk patients

- Nonassertive – the good patient
- Too social role conscious – meeting other’s expectations
- Need for harmony. Avoiding conflicts.
- Self-blame, guilt
- Bearing and tolerating the pain and suffering
Build death efficacy as well as pain efficacy

- Existential questions (we have to first work on ourselves, our own death fears)
Psychological pain management

- Cognitive Behavioral Therapy
- emotional expressions
- reduce negative mood
- enhance positive mood
- positive and relaxed attitude
- healing
- imagery, relaxation
- Hypnosis
- Narrative therapy
- family issues
- relational issues – relation matters a lot
- previous experiences with death & dying
Ethical aspects of pain management

- Die in fairly good consciousness
- Patient’s choice and perceived sense of control – pain management, social support, letting go, funeral arrangement, treatment options, what to expect
- Treatment options
- Advance directives
- Morphine – patient’s decision?
Ethical aspects of pain management

- If cancer pain as a reaction to inner psychic needs,

- by numbing out the pain by medications, are we taking away patients’ chance to explore their life hurts, pains, regrets & needs so that they could act upon these emotions before they die?
Further on Healing:

- building trust and communications
- sense of inner peace and hope
- acceptance
- what they could do about it
- quality of life
- what are the important things in their life?
- resource-building (e.g. life review)
Issue of control

- Waiting time – whose time is more important?
- Prioritize time
- No time to communicate – fear-avoidance of health care professional to address the core issues? Teamwork as diffusion of responsibility?
- Sometimes, pain blocks the human–human connection
- build up your competence in pain management.
supporting both patients and family
Cancer pain treatment

- is an interactive social process occurring between patients and health care providers (Meghani & Houldin, 2007)

- Sense making, meaning making, communication between patients and healthcare providers.
A prepared death is usually much better than a sudden death.

Therefore, be prepared very early on in life.
Thank You & Have a Good Life!

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