Psychiatric care of terminally ill Patients and their family members

Essay

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By

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CONTENTS

LIST OF ABBREVIATION

AMA	American Medical Association
CBT	Cognitive Behavioural Therapy
EOL	End of life
EUT	Euthanasia
FCG	Family Care Giver
FDA	Food and Drug Administration
HRQoL	Health Related Quality of Life
ICU	Intensive Care Unit
IDT	Hospice interdisciplinary team
NCP	National Consensus Project
NHPCO	National Hospice and Palliative Care Organization
NQF	National Quality Forum
NSRIs	Nor-epinephrine Serotonin Reuptake Inhibitors
PAS	Physician Assisted Suicide
PTSD	Post Trumatic Stress Disorder
QOL	Quality Of Life
RCTs	Randomised Controled Trials

SPIKES	A Six-Step Strategy for Breaking Bad News
TCA	Tri-Cyclic Antidepressant
WHO	World Health Organization

LIST OF TABLES

Terminal illness is a medical term popularized in the 20th century to describe a disease that cannot be cured or adequately treated and that is reasonably expected to result in the death of the patient within a short period of time. This term is more commonly used for progressive diseases such as cancer or advanced heart disease than for trauma. In popular use, it indicates a disease which will eventually end the life of the sufferer (Bayer.1984). The most common and debilitating of these terminal diseases are advanced metastatic cancer, which accounts for more than half of all hospice patients, irreparable organ failure, such as decompensated cirrhosis of the liver and uremia not amenable to dialysis, Stage IV congestive heart failure, irreversible respiratory failure, sepsis, and anoxic encephalopathy. A patient who has such an illness may be referred to as a terminal patient, terminally ill or simply terminal. Often, a patient is considered to be terminally ill when the life expectancy is estimated to be six months or less, under the assumption that the disease will run its normal course. The six-month standard is arbitrary, and best available estimates of longevity may be incorrect. Consequently, though a given patient may properly be considered terminal, this is not a guarantee that the patient will die within six months **(Glare et al. 2003)**. Kubler Ross **(1969)** outlined five distinct stages that are typical to the grieving process associated with a terminal diagnosis but not all people go through these stages in order and some do not necessarily experience all five stages. Kubler-Ross‘ five grief stages are: denial , anger, bargaining , depression and acceptance.

In general there are four main approaches to convey the message to patients about the reality of terminal illness. (1) wait the patient or the carer to raise the topic, (2) offer all patients and their carers the opportunity to

discuss the future, (3) Initiate the discussion when the patient and their family need to know , (4) the discussion can be initiated when the patient and/or their family seem ready **(Clayton . 2005).**

There was a debate whether to manage terminally ill patients at specific center or at home. 63% of patients and their family members preferred home as a place of death however that was not an available option in many cases **(krueger et al. 2005).**

There are two types of care can be used in terminal illness, palliative care and hospice care. Palliative care refers to patient and family centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative care throughtout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and delirium facilitating patient autonomy, access to information and choice **(Mahon &Kirk. 2010).** But hospice care includes medical, emotional, and spiritual support for patients, as well as their family members **(Holman et al. 2010).**

The prevalence of psychiatric disorders with terminal illness, within one week of admission, was 53.7% according to DSM-III-R criteria, 42% had cognitive impairment. 28% (26/93) had delirium, 10.7% (10/93) had dementia, 7.5% (7/93) had adjustment disorders, 3.2% (3/93) had amnestic disorder and major depression and 1.1% (1/93) had generalized anxiety disorder **(Derogatis et al. 2003).** Evidence of hopelessness, helplessness, worthlessness, guilt and suicidal ideation are better indicators of depression in terminally ill patients than neurovegetative symptoms. Although terminally ill patients often have suicidal thoughts, they are

usually fleeting. Sustained suicidal ideation should prompt a comprehensive evaluation **(Block&Cohen. 2004).**

Pharmacotherapy has a role in management of psychiatric comorbidity in terminally ill patients such as delirium,depression, anxiety, and other symptoms as pain, fatigue, anorexia, cachexia, nausea, vomiting, constipation and dyspnea, management of pain and psychiatric symptoms may give a great help to those patient. Delirium management was studied in 30 hospitalized AIDS patients receiving one of three different agents: chlorpromazine, haloperidol, and lorazepam. Analysis of this trial found chlorpromazine and haloperidol to be equally effective but chlorpromazine was noted to slightly worsen cognitive function over time but this result was insignificant. Lorazepam arm of the study was stopped early as consequence of excessive sedation **(Jackson et al. 2009)**, however medical oncologists use more pre-emptive therapies and more likely to use a benzodiazepine as agent of choice, but palliative medicine specialists used significantly more neuroleptics to treat hypoactive symptoms of delirium **(Agar et al. 2008).**

The pharmacologic treatment of depression in patients who are dying can be challenging. In some cases Psychostimulants, such as methylphenidate (Ritalin) or dextro-amphetamine (Dexedrine), can be helpful when a rapid response (within 24 to 48 hours) is desired. Also SSRIs are preferred agents for treatment of depression because they have a relatively rapid onset of action and fewer side effects, compared with tricyclic antidepressants, Patients can be started on a combination of a psychostimulant and an SSRI **(Block. 2000).**

The systemic review of Williams et al (2006) found insufficient trial data to judge the efficacy of either antidepressant or psychotheraby for treating major depression in cancer patient. Current evidence indicates that a variety of treatment models are helpful for training oncology to diagnose and treat depression in cancer patient such as excersice (Midtgaard et al. 2005) and cognitive theraby delivered by videophone to terminally ill patient **(Cluver et al. 2005).**

AIM OF THE WORK

This work is aiming :

- To review literature discussing “Terminally ill patients”.
- To review various strategies of care of terminally ill patients.
- To discuss the best guidelines about strategies of management of terminally ill patients to be applied in our country.

INTRODUCTION:

Human beings have conscious awareness of their mortality **(Langner, 2002),** and patients who have life-threatening illnesses are forced to face their mortality **(Emanuel et al. 2004**). The diagnosis of an incurable disease can trigger a profound existential crisis as everyday life and the future are threatened for both patients and their families **(Solomon et al. 2000).**

Terminal illness is a medical term popularized in the 20th century to describe a disease that cannot be cured or adequately treated and that is reasonably expected to result in the death of the patient within a short period of time. This term is more commonly used for progressive diseases such as cancer or advanced heart disease than for trauma. In popular use, it indicates a disease which will eventually end the life of the sufferer **(Bayer, 1984).** A patient who has such an illness may be referred to as a terminal patient, terminally ill or simply terminal. Often, a patient is considered to be terminally ill when the life expectancy is estimated to be six months or less, under the assumption that the disease will run its normal course. The six-month standard is arbitrary, and best available estimates of longevity may be incorrect. Consequently, though a given patient may properly be considered terminal, this is not a guarantee that the patient will die within six months **(Glare et al. 2003).** The most common and debilitating of these terminal diseases are listed in **table1**. Along with the progressive worsening of their illness, terminal patients face an increasingly complex set of care decisions and look to their health care providers to initiate and guide discussions about them **(Peppercorn et al. 2011).** At the same time, patient-centered care is better accomplished through a comprehensive understanding of patients' preferences for how they want to live their lives and how they want to

influence their own death process. The need to build a model of end-of-life care that begins with the patient's perspective and proceeds to deal with the conflicts and changes that happen with illness progression is often in opposition to the difficulties clinicians face when communicating about patient goals and expectations **(Knops et al, 2005).**

Table 1: list of some terminal diseases

Terminal diseases
1-Advanced metastatic cancer
2-Irreparable organ failure
a-decompensated cirrhosis of the liver
b-uremia not amenable to dialysis
c-Stage IV congestive heart failure
d-irreversible respiratory failure
e-anoxic encephalopathy
3-AIDS
4-Hemmoragic Fever
5-Lyme Disease
6- necrotizing fasciitis

(Barclay&Maher.2010)

EMOTIONAL ASPECTS OF TERMINAL ILLNESS

However, Patients will tend to keep with their pre-morbid personality and coping strategies during the course of the terminal illness. The reality of a terminal diagnosis can be overwhelming to a patient and family and many factors interact in a patient's will to live (**Tataryn & Chochinov, 2002**). In addition**, McCarthy et al. 2000**, studying patients with lung and colon cancer at terminal stages, found that there was more pain and confusion as death approached, but that patients were only moderately depressed and anxious during the last 3 days of life. The authors of this study highlighted opportunities to improve the quality of life at the end of life in patients dying of cancer. Such opportunities included careful evaluation and discernment regarding symptoms, comprehensive attention and treatment of psychosocial distress, and sustained contact with families of the patient.

Whereas, a study by **Fernsler et al** (**1999**) found that the demands of terminal patients and the associated stress were perceived to be greater in men, younger patients, and those who reported a decrease in activity or metastatic disease. A greater degree of psychosocial and spiritual well-being may help to mitigate the demands of such illness in the terminal stages, and therapists can foster efforts to facilitate the acquisition of such well-being as appropriate throughout terminal illness, and particularly at end stage, therapists need to respect the uncertainty that the patient feels regarding the possible course that the illness may take or length of life that can be expected. Although, hope is part of the emotional response to dying, and can be fostered and supported during the palliative phase (**Penson, 2000**), paying attention to the potential problems that may arise from false or unrealistic hope is not considered. Perhaps specific emphasis is needed on capturing the intangible, inner experience of hope,

and to validate the strategies that develop/maintain hope in patients and families (**Herth & Cutcliffe, 2002**) ,at the terminal stages of life as there may be multifaceted suffering, as the uncontrolled deterioration of one's body can be significant (**Finucane, 2002**).Therefore the choice between certain death, even if comfortable and dignified, and hope, is a difficult and painful choice that patients may have to make. **(Penson, 2000; Robertson, 2002**).

PSYCHOLOGY OF DYING PROCESS

It is important to note that during the dying process the patient is experiencing multiple losses: job, function, role in the family, daily routines, etc. There is loss of what might have occurred, loss of a career in its prime, or loss of the ability to see ones' children grow and mature. There may be the inability of the patient to see many of his/her life goals come to fruition. Therefore psychological reactions of the dying process are generally closely tied to the emotional aspects of terminal illness, but many factors may be contributory. Despite multiple efforts, researchers still struggle to identify outcome measures that adequately assess patients' and families' exact experience in dying (**Steinhauser et al. 2002**).

Terminally ill patients after receving the diagnosis of their illness pass in some stages which called grieving stages. Kubler Ross **(1969)** outlined five distinct stages that are typical to the grieving process associated with a terminal diagnosis but not all people go through these stages in order and some do not necessarily experience all five stages.