

Care of the Dying Patients: Doctors' Pivotal Job.

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Abstract:

Many diseases, esp. the chronic diseases, are incurable. That means that for a long time, doctors will be palliating the symptoms and when time comes, they would take responsibility for caring for dying patients. They should therefore prepare themselves to have discussions with patients and their families, manage their symptoms, support their families, diagnose dying, manage symptoms at the end of life, work in multi-disciplinary team and make decisions about withholding and withdrawing treatments to void patients' burden.

Text: Although all doctors work hard to cure ailments and save lives, dying from incurable diseases remain a basic fact of life. Despite the advent of modern treatments, most diseases in textbook remain incurable although these are, at best, controllable. Examples include Ischaemic Heart disease, Heart failure, Renal failure and cancer. There are diseases which cause immense burden on patients and are therefore requiring long-term symptom management and nursing support.

In this view, managing terminal phase of incurable diseases and death itself remains a healthcare professional's responsibility. In industrialized world and some developing countries like India, Palliative care has taken up that role but it is identified that providing palliative care is responsibility of all healthcare professionals (1).

Statistics of death in Pakistan:

World Health Organisation data shows that in 2010, life expectancy of Pakistan was 65 years, whereas healthy life expectancy was only 55 years (2). This means that for 10 years, doctors in Pakistan will have to manage patients with chronic symptoms and anticipate death. Pakistan is also shown to be 1st in the rank in terms of deaths from Syphilis, 4th in Rheumatic Heart disease, 7th in chronic lung diseases, 10th in Oral cancers and 17th in cardio-vascular diseases (Table 1).

TABLE - 1
PAKISTAN TOP 50 CAUSES OF DEATH
AGE-STANDARDIZED DEATH RATE
PER 100,000 POPULATION

S. #	TOP 50 CAUSES OF DEATH	Rate	World Rank
1	Coronary Heart Disease	222.95	17
2	Influenza & Pneumonia	133.31	32
3	Stroke	119.64	65
4	Lung Disease	68.21	7
5	Tuberculosis	56.58	31
6	Diarrhoeal diseases	55.21	42
7	Low Birth Weight	22.82	26
8	Diabetes Mellitus	22.40	116
9	Birth Trauma	19.94	22
10	Breast Cancer	19.33	58
11	Other Injuries	17.29	60
12	Road Traffic Accidents	15.55	94

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13	Liver Disease	15.48	54
14	Alzheimers/Dementia	14.33	20
15	Kidney Disease	12.28	117
16	Falls	12.17	9
17	Suicide	12.00	45
18	Rheumatic Heart Disease	11.71	4
19	Fires	10.87	5
20	Congenital Anomalies	10.01	14
21	Oral Cancer	9.40	10
22	Maternal Conditions	8.15	49
23	War	7.84	15
24	Lung Cancers	7.81	121
25	Peptic Ulcer Disease	7.75	34
26	Inflammatory/Heart	7.71	82
27	Hypertension	6.85	167
28	Syphilis	6.80	1
29	Stomach Cancer	6.66	97
30	Cervical Cancer	6.56	78
31	Oesophagus Cancer	6.17	42
32	Poisonings	5.91	36
33	Drug Use	5.38	12
34	Drownings	5.11	58
35	Asthma	5.09	82
36	Violence	4.97	99
37	Lymphomas	4.85	106
38	Meningitis	4.09	67
39	Colon-Rectum Cancers	4.08	149
40	Leukemia	3.61	112
41	Tetanus	3.47	11
42	HIV/AIDS	3.38	93
43	Hepatitis B	2.89	27
44	Bladder Cancer	2.86	80
45	Liver Cancer	2.69	172
46	Pertussis	2.66	24
47	Prostate Cancer	2.53	164
48	Ovary Cancer	2.36	81
49	Malnutrition	2.26	97
50	Leishmaniasis	1.94	6

The data from the United Kingdom suggests that Over half of people die in hospital (58%; an average of 277,055 per year), with only 19% dying in their own residence (an average of 90,517 people per year). It is also noted that 50% of those 19% will be anticipated deaths (3). There is no data available from Pakistan on places of death.

Managing terminal phase of death:

Hospitals all over the world are equipped to diagnose and manage diseases. Once a diagnosis is made, it is paramount that clinical team decides the aims of the treatment, which in majority of cases will be to control or cure the disease itself. However, once it is established that disease is incurable, it becomes duty of a doctor to ascertain, assess and manage the symptoms (Table 2).

Ref: World Health Organisation 2010

PREPARATION FOR DEATH
<ul style="list-style-type: none"> • Open discussion • Discussion with patient and those important to patients • Discuss place of care • Explore fears, concerns, beliefs • Symptom assessment and pre-emption • Symptom Management • Discussing withholding and withdrawing treatment including Cardio-pulmonary resuscitation, when appropriate • Respect patients and close people's decisions • Family issues and involvement • Multi-disciplinary approach • Pre-bereavement support

TABLE - 2

Discussions about prognosis:

It is often expressed that patients and their families do not want to hear bad news and therefore doctors do not break bad news due to fear of reaction. However, the data suggests that it is the *doctor's fear* which stops doctors to have those discussions. Multiple studies show that the stress of breaking bad news is greater among doctors when the clinician is inexperienced, when the patient is young, when the doctor and patient have a longstanding relationship, when strong optimism for a successful outcome had been previously expressed, and when the prospects for effective treatment are limited (4). However, it is now increasingly acknowledged that doctors have a duty to tell patients if patients wish to know diagnosis. A study demonstrated that all medical students and 96% of law students favoured information about the diagnosis of cancer if the patient requests it. 74% of medical students and 82% of law students favoured informing a cancer patient about his or her prognosis as well (5).

Having an honest discussion will facilitate good on-going care and achieve better psychological outcomes. One way of doing is to tell the patients and their families the diagnosis, possible treatment options and support them

by hoping for the best but preparing for the worst. Most times, exact prognosis is hard to tell anyway, but the discussion about the particular disease being incurable and although treatment with the aim of palliating symptoms while achieving some longevity should be explained.

Another issue, which is often raised, is that doctor-patient discussions are drawn from a western model and therefore may be not applicable for a culture like Pakistan. That would be true in terms of whom does patient want to be there on discussions as in west, there is usually one or two members of patients' contact present, whereas in Pakistan, there may be many different family members. However, when it comes to honesty, Islamic and Asian history has shown greater understanding of honesty to dying people. Qur'an writes: 'Oh you who believe! Fear Allah and be with those who are truthful' (6). In another place, it writes: 'Oh you who believe! Avoid suspicion as much as possible, for suspicion in some cases is a sin. And do not spy on each other, nor speak ill of each other behind their backs. Would any of you like to eat the flesh of his dead brother? No, you would abhor it' (7). As an example, one would remember Holy Prophet's grandson Hussein Ibn Ali, when he advised his fellow travellers that he would be slain and so would be the people who would accompany him (8). This was with confidence that their faith will help them cope with the news of death.

Diagnosing dying:

It is important to remember that in most advanced diseases, it is not just one organ which fails, but a combination of patho-physiology leads to death. This multi-organ failure can show itself with following developments:

- Cachexia
- Hepatic failure
- Renal failure
- Hypoproteinaemia
- Cytokines release e.g., TNF, IF etc.
- Loss of adipose tissue
- Deranged electrolytes (9)

This gives rise to various symptoms which in combination of the above findings can tell us that patients have only a short time i.e., days to small number of weeks to live. These symptoms include:

- Rapid deterioration
- Generalised weakness leading to being bed bound
- Difficulty with oral intake
- Central muscle loss i.e., temporal muscle loss or nasal cartilage loss leading to 'pinched nose'.
- Urinary and faecal incontinence
- Altered consciousness
- Increasing drowsiness
- Chest rattle due to inability to circulate interstitial fluids

Symptom management in last few days of life:

Although some symptoms can be disease specific e.g., breathlessness in Cardiac failure, most symptoms are

due to deterioration of body mechanisms regardless of primary diagnosis. Doctors should anticipate such symptoms and prescribe on as required basis, treatment of such symptoms. If taken repeatedly, regular medications should be given. Usually one can prescribe a Continuous Subcutaneous Infusion (CSCI) for such patients. However, in resource poor settings, these patients can be monitored on hourly basis and these medications can be given 4 - 8 hourly. Guidance for such symptoms is in Table - 3.

Table-3:

SUBCUTANEOUS OR INTRAVENOUS MEDICATIONS FOR SYMPTOM MANAGEMENT FOR INCURABLE DISEASES				
Symptom	Class of drugs	Examples	Starting dose	Comments
Pain	Opioids	Morphine	5 mg 4 hourly	Can be increased as no ceiling dose
		Tramadol	50 mg QDS	Maximum 400 mg / 24 hours
Breathlessness	Nebulisers	Salbutamol	2.5 - 5 mg QDS	
		Ipratropium	500 mcg QDS	
	Opioids	Morphine	5 mg 4 hourly	Slow titration helps in terminal breathlessness
Restlessness and agitation	Benzodiazepines	Diazepam	2 - 5 mg QDS	
	Neuroleptics	Haloperidol	1.5 - 3 mg TDS	
		Levomepromazine	12.5 mg BD	
	Barbiturates	Phenobarbital	60 mg TDS	Last resort for terminal agitation
Nausea and vomiting	Prokinetics	Metoclopramide	10 mg TDS	
	Antihistamines	Cyclizine	50 mg TDS	
	CTZ inhibitors	Haloperidol	1.5 - 3 mg TDS	
	Broad-spectrum	Levomepromazine	12.5 mg BD	
Fluid overload	Diuretics	Furosemide	40 - 80 mg OD	
Seizures	Benzodiazepines	Midazolam	2.5 - 5 mg QDS	Diazepam suppositories can also be used
Lung secretions and 'rattle'	Anticholinergics	HyoscineHydrobromide	400 mcg TDS	

An important message is to assess the patients at regular intervals as symptoms can change rapidly. Liverpool care pathway (LCP) is a good tool to make sure that symptoms are managed and families are kept adequately supported and informed (10). This tool is used when patients are deemed to be in their final days of life showing difficulty with their oral intake and having increased somnolence or unconsciousness. In 2004, NICE in the United Kingdom also suggested for LCP to be used in final stages of life. A 2009 survey of 42 carers of patients who were on LCP, found that 84% were "highly satisfied" with the approach and that it enhanced patient dignity, symptom management and communication with families (11).

Withholding and withdrawing treatments:

Withholding and withdrawing treatments are the hardest decisions towards the end-of-life. This is because doctors perceive it their duty to continue treatments and see withdrawal as their failure. However, most medical organisations agree that it is immoral and unethical to continue patients on futile treatments as these cause cumbersome burden and may increase symptoms (12). For example, it is not uncommon for a patient with end-stage Lung cancer to be on intravenous fluids and developing pulmonary oedema or a bed-bound elderly patient with end-stage leukaemia with intravenous antibiotics and developing severe oesophageal thrush with intractable pain.

An important step is to review all medications and stop medications which would not be helpful at this stage but

may increase metabolism making patients even more exhausted. These medications include statins, anti-parkinsonism medications, anti-hypertensives and hypoglycaemics (as usually patients' blood pressure and glucose is low at this stage). However, if withdrawal causes difficulties with symptom management e.g., corticosteroids withdrawal causing restlessness, then that would need to be reviewed.

Many patients would stop smoking at this stage but may get restless due to nicotine withdrawal. Doctors need to consider nicotine replacement at this stage, sometimes, with nicotine patches.

Many doctors resist deciding whether a patient should be for cardiopulmonary resuscitation (CPR). Whereas it is quite difficult to decide about patients with recurrent angina or renal failure, whether they will respond to CPR, it might be clearer for patients with widespread cancer. As it can be seen in Table - 4, success rate for cardiopulmonary resuscitation is very low and it would be even lower for advanced diseases. It is not appropriate to offer anyone treatment, for which there is such low evidence. One phrase which could be used to understand and decide about CPR is that it is a treatment for cardiac arrest and rhythm abnormalities and not for multi-organ failure or death.

TABLE - 4
SUCCESS RATE OF CARDIO-PULMONARY ARREST
(Ref. 13, 14 & 15)

Type of Arrest	Survival rate
Witnessed In-Hospital Cardiac Arrest	22%
Unwitnessed In-Hospital Cardiac Arrest	1%
Bystander Cardiocerebral Resuscitation	6%
Bystander Cardiopulmonary Resuscitation	4%
No Bystander CPR (Ambulance CPR)	2%
Defibrillation within 3-5 minutes	30%

Multidisciplinary Approach:

Caring for dying patients requires multidisciplinary care. Doctors provide symptom management, whereas nurses provide good pressure area care, mouth care, catheter care and bowel care. Many patients are incontinent towards the end of life and nurses need to help such patients to achieve patients' dignity and help them achieve a respectful death. In some cases, other family members who are going through a huge distress are also receiving medical care for their underlying diseases and sometimes even for depression. It is helpful to find out about their needs and suggest to them to seek advice from their caring team. A framework to look after non-physical needs would be following:

- Personal Hygiene
- Mouth care

- Pressure areas care
- Bedside attendance
- Religious / cultural rituals
- Support family and friends
- Encourage to get support for young children and elderly parents
- Respect patient's wishes
- Respect after death

Conclusion:

Caring for the dying patients is a part of doctors' job. Many doctors do not wish to do this as they look at this as a failure. Reality is that all doctors must do it and do it well. Death is the only sure thing in life as Quran also writes: 'Every soul shall have a taste of death' (16). Same connotation can be found in all scriptures. Sooner or later all of humans will meet this reality. If we do not treat our ill and dying with respect and dignity today, which would mean that we would be lacking good care ourselves in the future. If we as doctors create a culture of caring for the dying, society would certainly only progress in the future.

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