What I learned in Boston

Palliative Care Education & Practice (PCEP)

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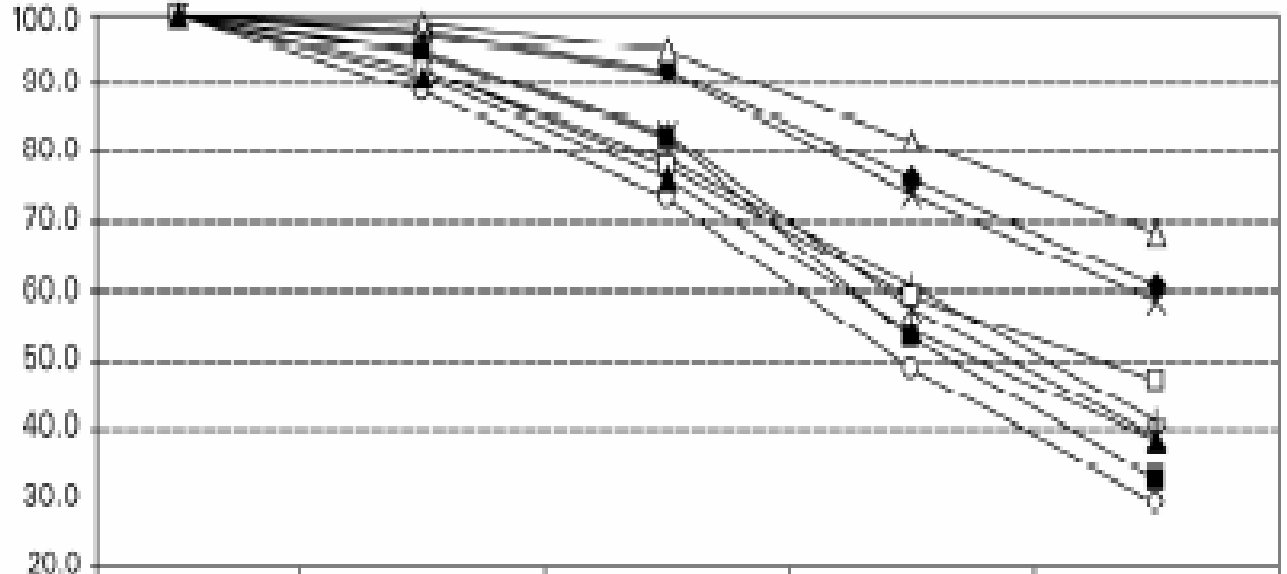
Figure 12. Unadjusted Three-Month and One-, Three- and Five-Year Survival in Dialysis Patients, by Etiology of Renal Failure, Canada, 1995 to 1999 (Followed to 2004)



	0	3 Months	1 Year	3 Years	5 Years
Glomerulonephritis	100.0	97.6	92.5	76.2	61.0
Diabetes	100.0	94.7	82.1	53.3	32.8
Polycystic Kidney	100.0	98.9	95.3	81.8	68.5
Pyelonephritis	100.0	97.0	91.8	74.0	58.9
Hypertensive Kidney	100.0	94.8	82.8	57.5	38.5
Renal Vascular	100.0	89.2	73.8	48.5	29.3
Drug Induced	100.0	92.1	79.3	61.1	40.9
Other	100.0	92.2	78.0	59.1	46.9
Unknown	100.0	91.0	76.3	54.0	38.3

Survival Time

Symptoms during Last 24 Hours

N=79

Symptom	% present
Pain	42
Agitation	30
Myoclonus/twitching	28
Dyspnea/agonal breathing	25
Fever	20
Diarrhea	14
Dysphagia	14
Nausea	13

Cohen et al. *AJKD*, 2000;36:140-144

Exposure to Palliative Care

	Geriatrics	Critical Care	Nephrology
Completed a Rotation Focused on Palliative Care	71%	2%	1%
Had Contact with Palliative Care Specialist	80%	46%	45%
Quality of teaching with respect to end-of-life care rated ‘very good’ or ‘excellent’	53%	34%	15%

Why the Nephrology Community should care about EOL care.
Alvin Moss MD. Center for ethics and Law. Section of Nephrology. West Virginia University.

Objectives

- Palliative care: a definition.
- A good death and a way to evaluate.
- How to share bad news.
- What is suffering?
- Hope.
- The “DNR”
- Cachexia, delirium, etc. and the ESAS.
- Pain and analgesics.
- Psychiatric consequences of terminal illness.
- Bereavement.

Palliative Care

A definition

- A comprehensive, interdisciplinary service, focusing on providing quality of life for patients living with a terminal illness and for their families.

PCEP

End of Life Care is just one aspect of Palliative Care

Palliative Care

What is a good death?

(Steinhauser et al. JAMA Nov 15, 2000. 284(19), p2476-2482)

- Free of pain
- Be mentally aware
- At peace with God
- In the presence of family
- Not a burden to family
- Treatment choices followed
- Finances in order
- Have funeral arrangements planned
- Not be a burden to society
- Resolve conflicts
- Feel one’s life is complete/legacy
- Die at home.

Quality of Dying in End-Stage Renal Disease

DIALYSIS QUALITY OF DYING APGAR (QODA)

Physical (symptom management) dimensions:

1. **Pain** (during the last week of life)

0= severe & distressing pain
1= the pain distressed the patient somewhat
2= no pain, or the pain did not distress the patient

2. **Non-Pain symptoms** (last week of life)
i.e.: confusion, dyspnea, spiritual distress, etc.

0= severe & distressing symptom
1= the symptom distressed the patient somewhat
2= no symptom or the symptom did not distress the patient

Psychosocial (peace) dimensions:

3. **Advance care planning**

During the last week of life, to what extent were patient's wishes followed- regarding a course of treatment that focused on extending life as much as possible even if it meant more pain and discomfort - or, on a plan of care that focused on relieving pain and discomfort as much as possible even if it meant not living as long.

0= formal health care proxy or living will had *not* been completed, documented, or communicated to staff who managed the terminal care.
1= intermediate
2= formal health care proxy or living will had been completed, documented, and communicated to staff who managed the terminal care.

4. **Peace/Dignity**

During the last week of life, did the patient die on his/her own terms? (Consider the following information, if available):

Was the patient lucid, coherent, able to take leave of loved-ones or have them say good-bye, complete most of the desired tasks, attend to spiritual matters, die where the patient chose, and leave the family united?

0= mostly <u>not</u> peaceful/dignified
1= mostly peaceful/dignified – intermediate
2= peaceful/dignified

5. **Duration dimension**

Time – Dying was prolonged or brief?

0= prolonged - in that the dying period lasted 6 months or more. If dialysis was discontinued, then death occurred 3 weeks or more after the last dialysis treatment.
1= intermediate - in that the dying period (terminal period) was less than 6 months but more than 1 month. If dialysis discontinued, death occurred between 2 and 3 weeks after the last dialysis session.
2= brief - the dying took place in sleep/suddenly/ unexpectedly, or occurred within one month of being in a terminal state. If dialysis was discontinued, then death took place 2 weeks or less from the time of the last treatment.

TOTAL DIALYSIS QODA SCORE _____
*(Mark the score with an asterisk *, if some aspect was unusual and warrants a narrative)*

PCEP

- How to give bad news
- How to listen
- How to use silence effectively during a patient encounter
- How to reframe goals to focus on the achievable
- Small things/words make a huge difference
- Know the patient as a WHOLE person…spiritual/religion
- “Culture” may be macro or micro

Talking with patients about a life-threatening illness.

- Hearing bad news: “How did you find out?”
- Information sharing and prognosis.
- Effects of the illness on the **person**.
  The experience, physical, emotional, concerns, surprises.
- Past, present and future.
- Supports: Informal and formal.
- Spirituality.
- Facing the reality: thoughts about death and dying

  Plans: practical: will, affairs, burial, SDM, AD.

Talking with patients about a life-threatening illness.

- Personhood and how has this been affected.
- Reconciliation and closure:
  how to make the events meaningful,
  saying the previously unsaid,
  saying goodbye.

- Legacy

Sharing bad news

- Appropriate setting
- Prepare yourself (rehearse key points)
- Consider involving family/SDM **(ask the patient)**
- Begin by aligning knowledge
- “Warning shot”
- Be brief and simple **(key message)**
- Be honest- avoid false reassurances
- Listen- allow time for patient to respond **(tolerate silence)**
- **Listen…affirm…pause…listen**
- Convey support/caring **(touching is OK)**
- Offer next steps
- Communicate with team/document the discussion.

PERSPECTIVES ON CARE AT THE CLOSE OF LIFE

Establishing Trust With Hospitalized Patients

- Encourage Patients and Families to Talk
- Do Not Contradict or Put Down Other Health Care Providers, Yet Recognize Patient Concerns
- Acknowledge Errors
- Be Humble
- Demonstrate Respect

PERSPECTIVES ON CARE AT THE CLOSE OF LIFE

Establishing Trust With Hospitalized Patients

Taking care of patients in the hospital often requires physicians to develop relationships quickly and does not allow much time to engender trust through experience. The following may help:

- **Encourage Patients and Families to Talk**

- "Tell me what you understand about your illness."
- "We've just met and there is so much going on with you right now. To help me get to know you better, can you tell me about your life outside of the hospital?"
- "I'm sure that this illness has been a lot to absorb quickly. How are you coping with this?"

PERSPECTIVES ON CARE AT THE CLOSE OF LIFE

- **Do Not Contradict or Put Down Other Health Care Providers, Yet Recognize Patient Concerns**
- "I hear you saying that you didn't feel heard by the other doctors. I'd like to make sure that you have a chance to voice all of your concerns."
- "It sounds like Dr Jones left you feeling very hopeful for a cure. I'm sure he really cares about you, and it would have been wonderful if things would have gone as well as he wished. "

PERSPECTIVES ON CARE AT THE CLOSE OF LIFE

- **Acknowledge Errors**
- "You're absolutely right. Four days was too long to have to wait for the CT scan. Any excuses we have won't make you feel better.“

PERSPECTIVES ON CARE AT THE CLOSE OF LIFE

- **Be Humble**
- "I really appreciate what you've shared with me about the side effects of the medication. It's clear that the approach I had suggested is not going to work for you."

PERSPECTIVES ON CARE AT THE CLOSE OF LIFE

- **Demonstrate Respect**
- "I am so impressed by how involved you've been with your father throughout this illness. I can tell how much you love him."

Suffering

Suffering

- A symptom is not suffering
- Loss of personal integrity is suffering

Suffering

Loss of integrity as a person.

- Loss of self-esteem
- Loss of privacy
- Loss of control/change of bodily functions
- Loss of intellect
- Abandonment
- Loss of physical capabilities
- Uncontrolled pain
- Uncontrolled nausea

Hope and the prospect of healing at the end of life.

C. Feudtner JACM Vol 2, Suppl 1, 2005, S23-S30

- Human healing represents the attainment of an holistically conceived health-related goal.
- Individuals experience hope when they have an expectation that a desired goal can be achieved.

Addressing Hope Explicitly

- “What are you hoping for?”
- “How are these hopes faring?”
- = the point of empathic entry.

Hope

- Framing
- Anchoring
- Revising the frame, resetting the anchor:
  i.e. “re-goaling”

- “Is it time to emphasize different goals?”

Aspects of hope/fear

- Identity, meaning and life story narratives.
- Self-efficacy and loss of control.
- The threat of senselessness.

Hope

- Hope is a powerful influence in our lives.
- Hope is potentially everywhere, including at the bedside of someone dying.
- When mobilized effectively, hope is precious.
- Patients and families care intensely about hope.

PCEP

- DNR / DNAR / DNI / AND
- AND….allow natural death

DNR: discussion and resolution

- Answer “miracle” wish with “I wish that were possible”
- What is the best way to love your…….?
- Redirect energy for cure to energy to fight for the comfort of the patient
- NB when talking to family, DO NOT say: “What kind of person WAS your husband.”

DNR: discussion and resolution

- Strive for mutual understanding
- Clarify goals
- Build an alliance with patient and family
- Make a recommendation:

  informs family that such an option is legal, moral, compassionate
- Avoid “do you want everything done”
- Emphasize on-going care, no abandonment
- Shift in goals of care
- When conflict, discover the REAL issue

DNR discussion

Mrs A.

We haven’t approached the way he died. It was absolutely disgusting…that pushing him constantly as to whether he wanted heroic measures of care. We had a lot of irritation. It was insensitive. He had made his wishes clear – he did not want valiant measures.

Recognizing and managing affect in an emotionally charged environment.

Managing Affect

- Declare the obvious re the present (sadness, frustration, anger)
- Explore the future & its emotions
- Empathetic agreement (expression of wishes)

Psychiatric consequences of a Terminal Illness

50-65% patients with advanced disease have a psychiatric disorder, most commonly:

- Adjustment disorder 11-35%
- Major depression 5-26%
- Anxiety disorder 6-14%
- High comorbidity 7.5-35%

Miovic M, Block S. Cancer 2007: 110(8)

Adjustment disorder

- May include anticipatory grieving
- Emotional/behavioral sx's in excess of normal for a given stressor.
- Demoralization.
- Situational anxiety/depressive sx's below syndromal threshold.
- SSRIs ineffective
- Control symptoms, search for meaning, dignity

Grief vs Depression

Grief

- Normal response to loss
- Mild neuro-veg symptoms
- Comes in waves
- Fleeting or passive SI
- Ability to enjoy life and plan
- Can still find meaning
- Crying is an emotional release

Depression

- Abnormal response
- Prominent neuro-veg symptoms
- Constant hopelessness
- Frequent or active SI
- Anhedonia, guilt++, future bleak
- Hard to find meaning
- Crying is draining
- Sustained irritability and/or anger

Supporting the survivors.

- **Reassure** family members that their response to the patient's death is normal.
- **Listen** sympathetically if they wish to review the circumstances of the patient's death.
- Reassure the family that you will **remain available** to them to help them with their grieving.
- During the first year **call or write** to the family at regular intervals, don't wait for them to make contact.
- **Offer** to send educational materials on manifestations of grief, coping techniques and professional resources, if the family wish.
- Invite the family to participate in a **memorial** service.
- Identify family members at **high risk for prolonged, intense grief** and arrange a referral for professional support even before that patient dies.

Patient

Mr A.

78 years old.

Long H/O Diabetes, hypertension, CAD, CHF, ESRD, dies in renal failure after a 10 week hospitalization.

Anger

Mrs A.

We haven’t approached the way he died. It was absolutely disgusting…that pushing him constantly as to whether he wanted heroic measures of care. We had a lot of irritation. It was insensitive. He had made his wishes clear – he did not want valiant measures.

Bereavement

Mrs A.

My husband's doctor….as soon as my husband died, that was the end of him. That's one of the things that I object to: all the doctors suddenly go…there's no support.

Bereavement Call

- Suggested texts when telephoning bereaved relatives after a death.
- Hello Mrs/Mr/.....
- This is Dr.....calling. The purpose of my call is to offer my condolences to you and your family after the death/passing of .....
- It has been/was a privilage to have been associated with the medical care of ..... for the last.....months/years. I have been impressed by his/her strength in the face of his/her illness and the dignified way in which he/she faced the final stages of his/her life. This has been an inspiration to me, my medical and nursing colleagues, and the other patients who so valued their association with him/her. .....will be missed by his/her renal/dialysis “family”.
- This must be a very busy and difficult time for you, so I do not want to take up too much of your time, but please don't hesitate to contact me, or one of the other members of the renal team if there is anything we can help you with.

Writing a condolence letter.

- Acknowledge the loss and name the deceased.
- Express your sympathy...remind the bereaved that they are not alone in their grief.
- Note special qualities of the deceased.
- Recall a memory of the deceased.
- Remind the bereaved of their personal strengths.
- Offer help, but be specific and be prepared to follow through.
- End with a word or phrase of sympathy.

Writing a condolence letter.

Dear

I felt that I wanted to write to you because I have been thinking increasingly about your late husband/father/brother/sister/mother _____ as I walk through the wards of St. Paul's/VGH/other hospital.

I fondly remember _____ courage and humour despite the seriousness of his/her illness. I remember too his/her unfailing love of the work he/she did and how he/she placed a photograph of_____near his/her bed in the ward at __ Hospital.

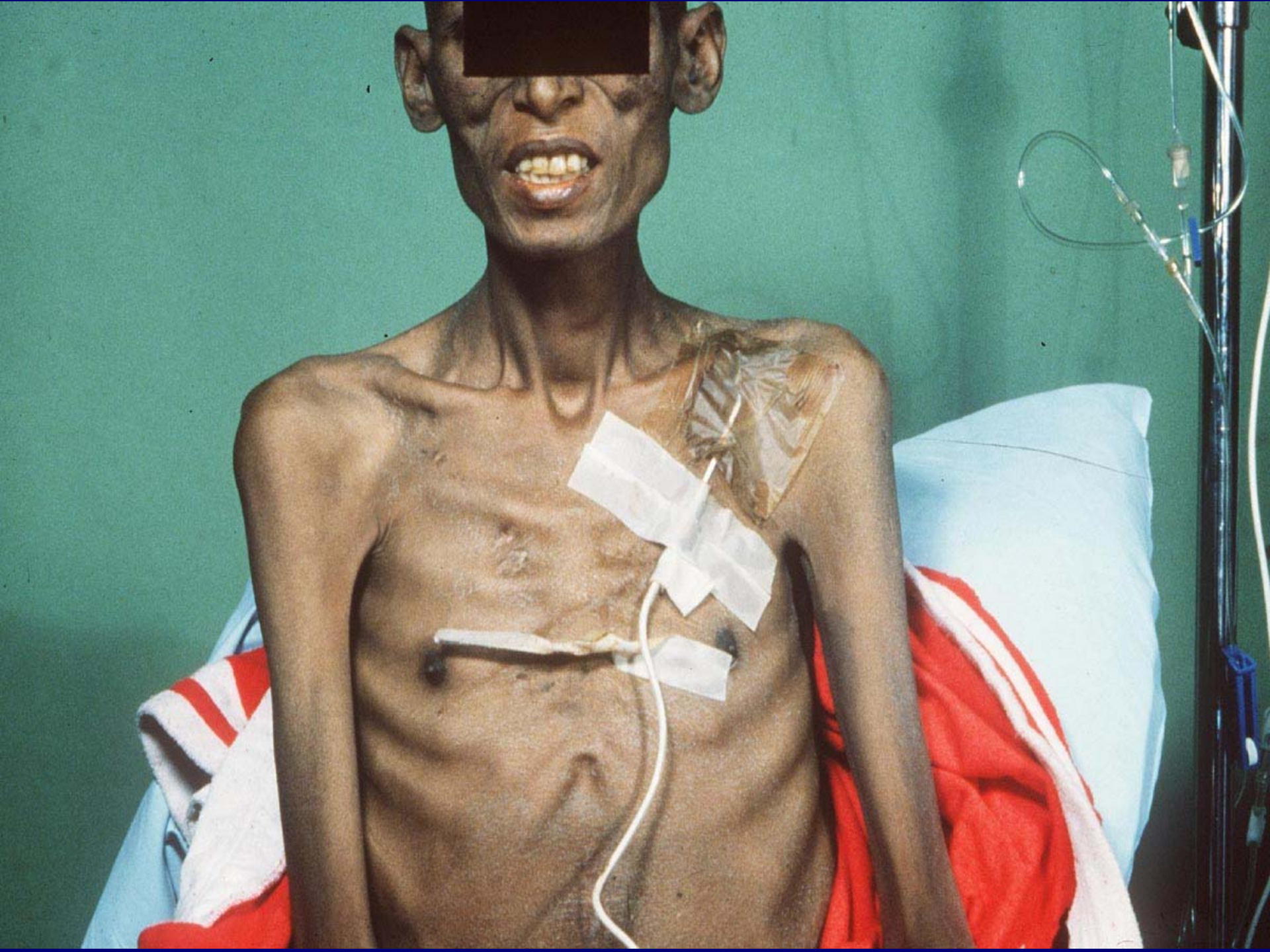
His/her strength has left an indelible memory and has once again taught me how the human spirit can overcome almost all adversity.

I hope that you and your remarkable children are finding your own strength to overcome your loss.

With fondest regards.

Yours sincerely,

Cachexia, delirium, etc. and the ESAS



Let's Interpret This Picture

Assumption

- TPN for malnutrition

In Actuality

- Malnutrition is NOT the problem, catabolism and protein breakdown due to tumour cytokines, inflammation, etc… is the issue.

Symptom and Signs

- Anorexia
- Nausea
- Cachexia
- Asthenia, depression, delerium.

  Common to most terminal illnesses, neoplastic, heart failure, renal failure, TB
- Leptin, Ghrelin, CCK.

  Tumour byproducts, metabolites, electrolytes, inflammatory cytokines and brain function!

Symptoms during Last 24 Hours

N=79

Symptom	% present
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Cohen et al. *AJKD*, 2000;36:140-144

ESAS

Capital Health

Edmonton Symptom Assessment System:
Numerical Scale
Northern Alberta Renal Program

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No itching	0	1	2	3	4	5	6	7	8	9	10	Worst possible itching
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
No problem sleeping	0	1	2	3	4	5	6	7	8	9	10	Worst possible problem sleeping

Patient's Name _____

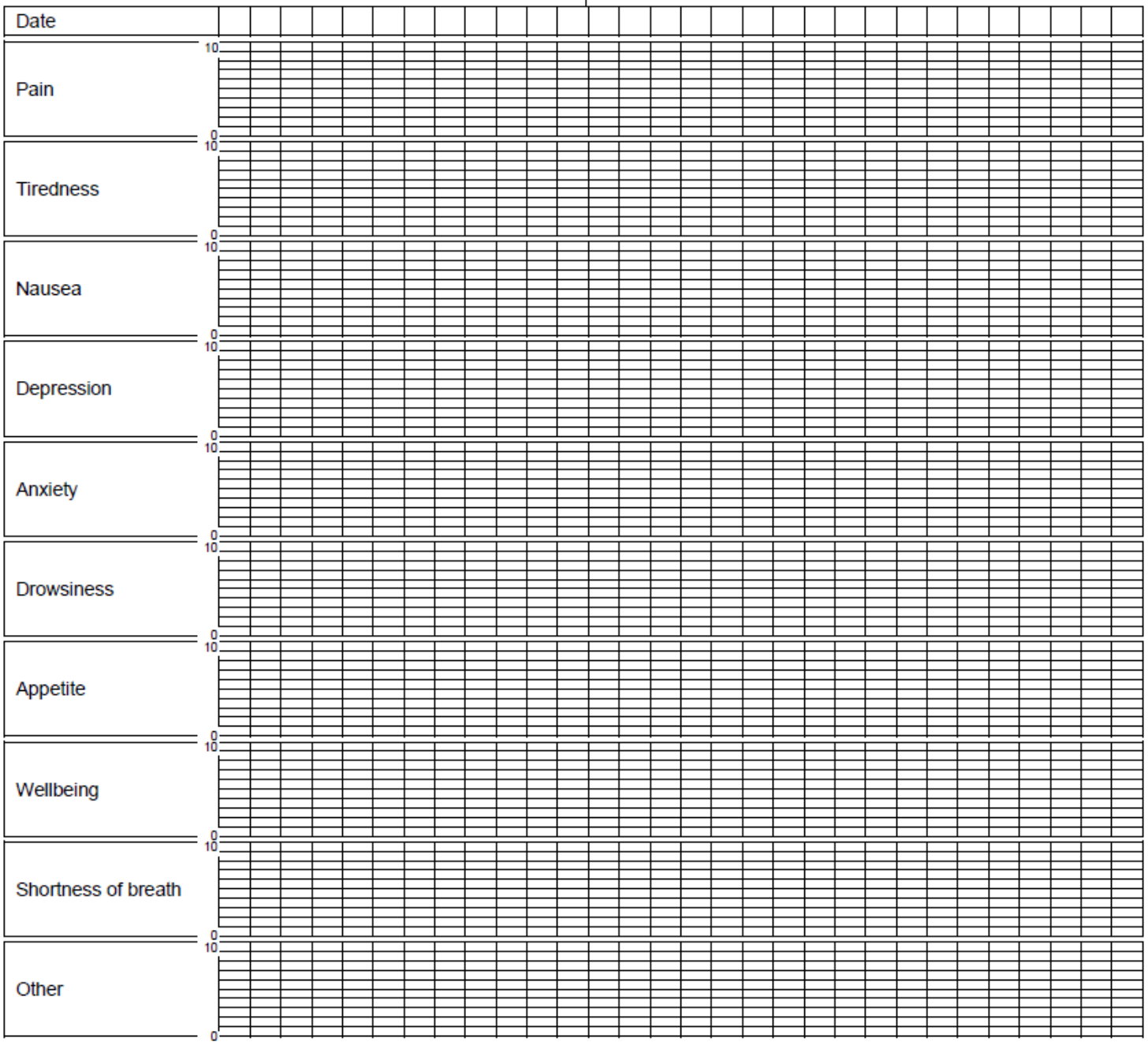
Date _____ Time _____

Complete by *(check one)*
- ☐ Patient
- ☐ Caregiver
- ☐ Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

April 12, 2002 C:\Data\Nephrology\Edmonton Symptom Assess Numerical Scale.doc

Edmonton Symptom Assessment System Graph
(ESAS)



Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment.

A.A. Wright et al *JAMA.* 2008;300(14):1665-1673

Advanced Cancer Patients. 123/332 (37%) had EOL discussions.

- NO increased rate of depression 5.8% vs 8.3% OR 1.33
- NO increased rate of worry 6.5% vs 7.0% p = 0.19
- Decreased rates of

Ventilation	1.6% vs 11.0%	(p = 0.02)
Resuscitation	0.8% vs 6.7%	(p = 0.02)
ICU admission	4.1% vs 12.4%	(p = 0.02)
Hospice care	5.6% vs 44.5%	(p = 0.03)

EOL Discussions

More aggressive medical care led to:

- Worse patient QOL (K score) 6.4 vs 4.6 (p= 0.01)
- More depression in the bereaved O.R. 3.37 (CI 95%)
- Hospice QOL 6.9 vs 5.6

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