

The Role of Palliative Care Medicine in Advanced CKD

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- What is pall care?
 - Structure of services
 - Evolution
 - Components of care
- Renal palliative care – what's different?
 - Tallaght experience
- Dialysis – mortality and morbidity
- Advance care planning
 - Breaking bad news
 - Preserving hope

“Palliative care is ... concerned with ordinary people who find themselves facing extraordinarily difficult situations: the loss of independence, the loss of financial security, the loss of all that is safe and familiar, the loss of friends and family, the loss of future and ultimately, the loss of life.”

National Advisory Committee on Palliative Care,
2001

- “Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light.”
 - *Dylan Thomas*
- “A dying man needs to die, as a sleepy man needs to sleep, and there comes a time when it is wrong, as well as useless, to resist.”
 - *Stewart Allsop*

- “There are two distinct respects in which one's dying can go awry. One may do it in a bad way, and one may do it at a bad time.”

– “*Doctors Dilemmas – Moral Conflict and Medical Care.*” *Samuel Gorovitz*

Palliative Care

- Symptom control
- Advance (and end of life) care planning
- Psychological support and education to patients and families
- Bereavement care

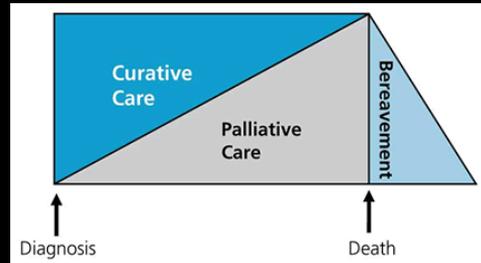
- Collaborative
- Multidisciplinary – physio, OT, social work, psychology, chaplaincy, pharmacy...
- Hospital, Hospice and community teams
- “Doing simple things well”

Specialist palliative care services

- Hospital consult services
- Community services
 - Home care
 - Day hospice
 - OPD
- In-patient hospice care

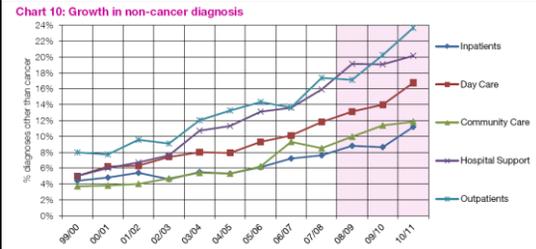
2013 Eligibility criteria for access to Specialist Palliative Care (SPC) services

- Patients with both
 - An advanced, progressive, life-limiting condition and
 - Current or anticipated complexities relating to symptom control, end of life care-planning or other physical, psychosocial or spiritual needs that cannot reasonably be managed by the current care provider(s)

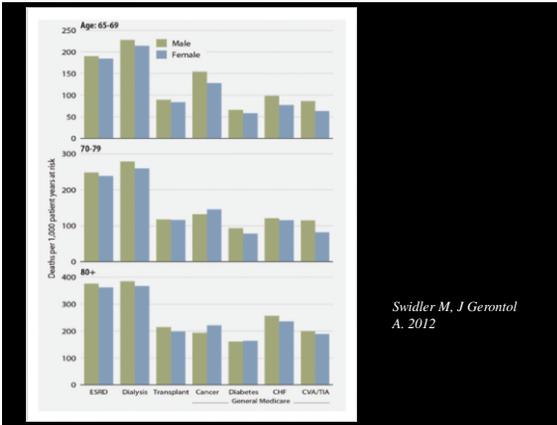


Evolution of Palliative Care

- Prognosis based
- Diagnosis based
- Needs based



- National Council for Palliative Care UK



Who needs renal palliative care?

- Opt for conservative care
- Deteriorate gradually on dialysis
- Dialysis effective but underlying condition progresses (eg PVD, diabetes)

Triggers for identifying patients approaching the end of life

- At time of decision for conservative kidney management
- Around decision to withdraw from dialysis
- Deteriorating despite dialysis
- Time of crisis e.g. stroke, malignancy
- Other life threatening condition eg malignancy
- Failing transplant
- Surprise Question

"Would you be surprised if this person were to die during the next year?"

End of Life Care in Advanced Kidney Disease – A Framework for Implementation. NHS, 2009

- 147 dialysis patients
- Asked nurse practitioner "Would you be surprised if this patient died in the next year?"
- 12 month mortality rate:
 - "No" 29.4 %
 - "Yes" 10.6 %
- Utility of the "Surprise" Question to Identify Dialysis Patients with High Mortality. Moss, 2008

- Deaths of patients on renal replacement therapy (HD or PD) between 2005 and 2009
 - N = 131
 - Duration on dialysis – 25 months (median)
 - Mean age at death – 63
 - Referred to SPC – 36.7%
 - Median duration from referral to death – 12 days
- Redahan, Clin Kidney J. 2013

- Place of death
 - Acute hospital 79.4% (43% in general population)
 - Home 14.5%
 - Hospice 2.3%
 - Unknown 3.8%
- Median total in-patient stay in last year of life – 53 days
- Redahan, Clin Kidney J. 2013

- Dialysis withdrawn – 38% (50)
- Documented discussion re withdrawal of care
 - With patient only 4%
 - With patient and family 18%
 - With family only 64%
 - No documented discussion 14%

– Redahan, *Clin Kidney J.* 2013

- What’s different about *renal* palliative care?



Haemodialysis

Dr Willem Kolff

March 17th, 1943

- 1962 - first outpatient haemodialysis treatment centre
- “To treat eleven patients, the Seattle Artificial Kidney Center has a staff of two fulltime physicians and one halftime, plus five nurses and five technicians.”
- The “Life or Death Committee”

Time Magazine, April 24, 1964

Selection criteria for patients “suitable” for dialysis

- Age 20-45
- Without systemic disease
- Without severe hypertension
- Preferably with some residual renal function
- Emotionally stable
- Co-operative
- Live within reasonable distance of dialysis unit
- Have a job, or be studying or looking after family
- “worthiness”

- How to ration dialysis.....?
- How to dialyse rationally....?

- “Dialysis is a life-sustaining therapy that behaves like a chronic progressive illness accelerated aging.”

• Swidler M, *J Gerontol A*. 2012

Expected remaining years for US general & dialysis populations by age in > 60, 2008

Age	General population	Dialysis
60-64	21.0	4.6
65-69	17.2	3.9
70-74	13.8	3.3
75-79	10.8	2.8
80-84	8.2	2.3
85+	4.4	1.9

Source: USRDS, 2008, ADR

- Tamura M. Functional status of elderly adults before and after initiation of dialysis. *NEJM* 2009.
- 3702 USA nursing home residents who started dialysis
- Mean age = 74
- After 12 months
 - 13% maintained pre-dialysis function
 - 29% deterioration in functional status
 - 58% died

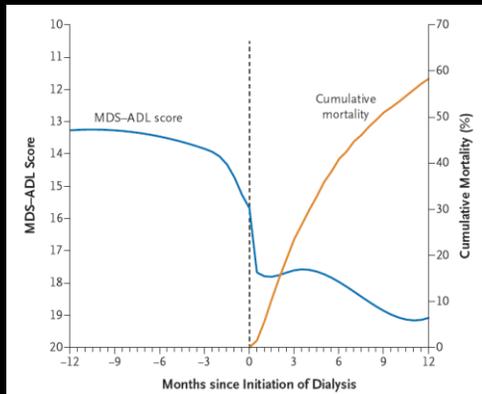
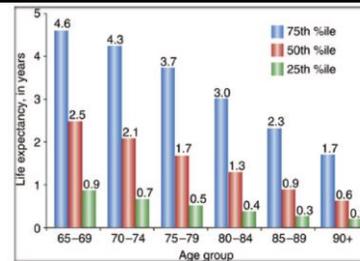


Table 3 Symptoms prevalence in ESRD patients

Symptoms	No. of patients			P-value
	Total (N=179)	Dialysis group (n=134)	Palliative care group (n=45)	
Fatigue	132 (73.7%)	101 (75.4%)	31 (68.9%)	0.302
Cold aversion	127 (70.9%)	92 (68.7%)	35 (77.8%)	0.244
Pruritus	114 (63.7%)	88 (65.7%)	26 (57.8%)	0.341
Lower torso weakness	106 (59.2%)	80 (59.7%)	26 (57.8%)	0.820
Difficulty sleeping	105 (58.7%)	83 (61.9%)	22 (48.9%)	0.124
Skin changes	86 (48.0%)	73 (54.5%)	13 (28.9%)	0.003*
Limb numbness	86 (48.0%)	67 (50.0%)	19 (42.2%)	0.366
Dry mouth	78 (43.6%)	61 (45.5%)	17 (37.8%)	0.365
Cough	76 (42.5%)	57 (42.5%)	19 (42.2%)	0.970
Pain	73 (40.8%)	51 (38.0%)	22 (48.9%)	0.235
Loss of appetite	73 (40.8%)	60 (44.8%)	13 (28.9%)	0.061
Muscle cramp	68 (38.0%)	53 (39.6%)	15 (33.3%)	0.457
Dizziness	62 (34.6%)	49 (36.6%)	13 (28.9%)	0.349
Dyspnea	61 (34.1%)	40 (29.9%)	21 (46.7%)	0.039*
Haltosis	53 (29.6%)	45 (33.6%)	8 (17.8%)	0.045*
Limb swelling	53 (29.6%)	39 (29.1%)	14 (31.1%)	0.799
Constipation	53 (29.6%)	37 (27.6%)	16 (35.6%)	0.313
Sexual problem	50 (27.9%)	46 (34.3%)	4 (8.9%)	0.001*
Bloated abdomen	47 (26.3%)	37 (27.6%)	10 (22.2%)	0.477
Nausea	35 (19.5%)	30 (22.4%)	5 (11.1%)	0.243
Change in taste	33 (18.4%)	26 (19.4%)	7 (15.6%)	0.555
Hearing impairment	31 (17.3%)	25 (18.7%)	6 (13.3%)	0.414
Restless leg	23 (12.8%)	17 (12.7%)	6 (13.3%)	0.911
Mean no. of symptoms (SD)	9.1 (5.0)	9.3 (4.7)	8.2 (3.9)	0.243

Yong DSP, Palliative Medicine, 2009



Expected remaining lifetimes US general population in yrs. (from n 3):

- 80-84 : 8.75
- 85-89 : 6.5
- 90-94 : 4.5

Figure 2. Quality of Life expectancy after dialysis initiation by age group (37). Reprinted with permission.

Geriatric assessment

- Chronological age
- Karnofsky score
- Activities of daily living (ADLs)
- Instrumental activities of daily living (IADLs)
- Geriatric self-health questionnaire
 - Vulnerable Elders Survey (VES-13)
- geriatric syndromes screening
 - walking speed
 - chair rise
 - frailty testing
 - cognitive testing
 - falls assessment
 - depression screening
 - nutrition assessment

Renal specific prognostic tools

- modified Charleson Co-morbidity score
- Surprise Question
- hemodialysis mortality predictor
- French Renal Epidemiology and Information Network Registry 6-month Prognosis Clinical Score
- Is this patient from a nursing home?

Swidler M, J Gerontol A. 2012

<http://touchcalc.com/calculators/sq>

- Serum albumin
- Dementia
- PVD
- “Surprise question”
- Age

Healthy/usual:

- Karnofsky scores ≥ 80 ; VES-13 ≥ 3
- no significant geriatric syndromes; non-frail
- perform well on ADLs and IADLs
- answer to Surprise Question is No
- low co-morbidity scores (CCI ≤ 4)

Vulnerable:

- Karnofsky 50-80; VES-13 4-9
- varying degrees of ADL/ IADL/ geriatric deficits
- moderate co-morbidity scores (CCI 5-7; FEN clinical score < 9)
- increasing hospitalizations and unpredictable outcomes
- overlap/transition to frail/in some answers to Surprise Question might be “maybe” or “I don’t know”

Frail:

- Karnofsky < 50 ; VES-13 ≥ 10
- positive frailty testing, notable ADL and/or IADL deficits, multiple geriatric syndromes
- significant symptom burden
- “Would you be surprised if this patient died in the next year?” No
- low survival probabilities by co-morbidity scores (CCI ≥ 8 , FEN clinical score ≥ 9) and hemodialysis mortality predictor
- Nursing home ACKD or dialysis patient

healthy dialysis phenotype

- name Health Care Proxy using proper form
- review and update any previous Advance Directives
- keep ACP discussion general unless patient with specific preferences (e.g. Jehovah’s witness)
- document any discussion of goals and wishes for medical treatments in life threatening conditions
- emphasize flexibility regarding future unpredictable events

vulnerable dialysis phenotype

- initiate ACP discussions with “big picture” goals
- use patient’s recent hospitalization as a spring-board:
 - “if you get sick again or cannot make decisions, what would be important to you?”
 - “How was your experience in the ICU? What was it like being on the ventilator?”
 - “Would you go through that again? Under what circumstances? What change in your level of function would you accept?”
- appoint Health Care Proxy
- complete Advance Directives
 - Target specific therapies:
 - mechanical ventilation if significant COPD or
 - Do Not Resuscitate/Feeding tube if advanced cardiomyopathy or progressing dementia
- symptom assessment

Swidler M, J Gerontol A. 2012

“Frail dialysis phenotype”

- at high risk for decisional incapacity; appoint Health Care Proxy imminently
- update “big picture” goals and revise medical plan:
 - “Since his prolonged hospitalization last month, Mr. S. lost his ability to transfer and requires a feeding tube. His dialysis team met with him and his Health Care Proxy to update goals of care. Given the significant change in his status and his desire to minimize suffering, in case he ever developed serious breathing problems, Mr. S. chose to be treated with medicines and not be put on a breathing machine.”
- initiate DNR discussions with language the patient can understand:
 - “When a person stops breathing or their heart stops, they have died. Resuscitation is an attempt to bring them back to life. If it was your time to go, would you want to go peacefully and naturally, (be taken by God if religious) or would you want your doctors and team to interfere in that unique moment?” Are there different circumstances when you would want your team to bring you back or not?”
- if severely frail, resides in a long-term care facility, or requires significant long-term care complete Physician Orders for Life-Sustaining Therapy order form
- documents should be easily accessible and families have copies

Swidler M, J Gerontol A. 2012

- Advance care planning ... a process of ongoing communication to regularly update prognosis, goals of care and individual life and quality preferences as the trajectory of decline progresses and EoL issues become more prominent”

- Swidler M, J Gerontol A. 2012

- “As a minimum, advance care planning should start when the answer to the “surprise” question is “no” (would I be surprised if this person died within the next 6-12 months?).”
- Kane P, Palliative Medicine. 2013

- “.....Patients undergoing dialysis typically do not view themselves as terminally ill and falsely assume they can be kept alive indefinitely on dialysis”
- Davison S, BMJ. 2006

- “Patients need to plan and make decisions about the place of their death, put their affairs in order, say good-byes or forgive old adversaries and be protected from embarking on futile therapies.”

Fallowfield, 2002.

Breaking bad news

- Gradual disclosure
- Gentle honesty

Breaking bad news

- “Verbal surgery”
 - Preparation
 - Innate ability and training
 - Appropriate setting
 - Takes time
 - Will always be some scarring
 - Can go seriously wrong – even when you do everything right

- Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers

– Clayton J, J Aus Med Assoc. 2007
(hospicefoundation.ie – advance care planning)

- Hope for
 - a miracle cure
 - a peaceful death
 - both
 - Any point in between
- Hopes change and helping patients and families develop new hopes is a key part of palliative care

Strategies to facilitate hope and coping

- Reassure that support will be available
- Emphasise what can be done – specifically in relation to pain and other symptoms
- Be realistic about what you can do
- Explore and help facilitate the creation and realisation of realistic goals
- Discuss different ways of coping and respect the patients' ways of coping (including denial)

- "...*quality of life* measures the difference, or the gap, at a particular period of time between the hopes and expectations of the individual and that individual's present experiences."

- KC Kalman 1984

"Still, a man hears what he wants to hear, and disregards the rest."

Simon & Garfunkel 1968

Characteristics of good palliative care for renal patients

- Collaborative – between different disciplines and specialties
- Tailored – to that patient and that family
- Timely (Temel....)

- Radiation....