

Did this patient die with hospice?

New questions in caring for patients with ESRD



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Renal Palliative Care Initiative

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Objectives



- Describe characteristics of the end-stage renal population
- List palliative care needs of the end-stage renal population
- List critical elements of a program for providing hospice care to patients and families facing end-stage renal disease
- Describe strategies for working with dialysis centers and nephrologists



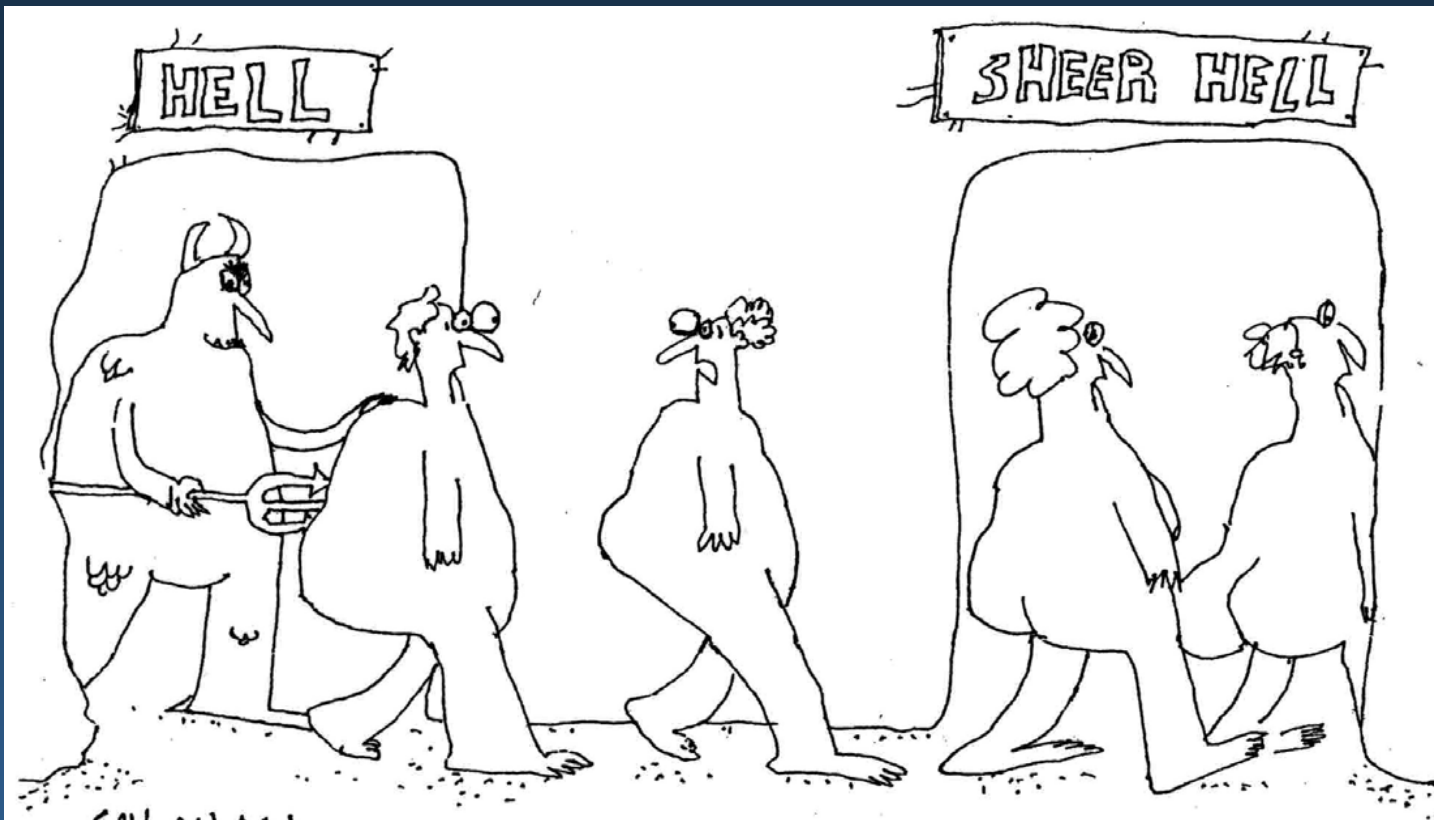
Insights into renal patients and nephrologists

Lewis M. Cohen, MD

Why offer palliative care and hospice services in ESRD?



- Heavy symptom burden
- High mortality rate
- High discontinuation of dialysis rate
- Poor quality of dying



CALAHAN

"Just when I thought things couldn't get any worse!"

Heavy symptom burden (N=80)



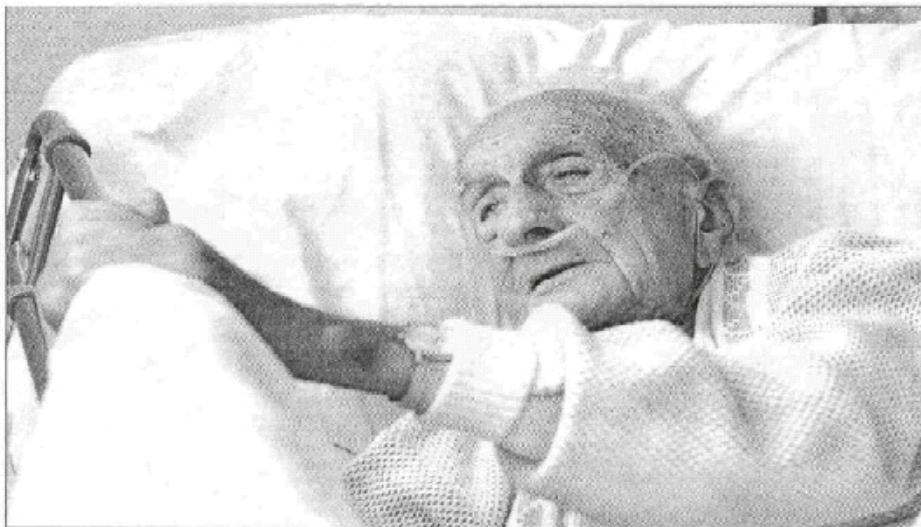
- fatigue- highest endorsed
- insomnia (38%)
- cramping (36%)
- pruritis (35%)
- neuropathic symptoms (29%)
- poor spirits (24%)
- N&V (20%)

Cohen et al., unpublished. See Cohen LM, Levy NB, Tessier E, Germain M: Renal Disease. American Psychiatric Publishing Textbook of Psychosomatic Medicine, Levenson J (ed), American Psychiatric Publishing, Inc.

High mortality rate



- Annual rate (23%) or $> 70,000$ deaths
- 16%-37% life expectancy (age and sex matched)
- Risk of death of a 45 year old patient with ESRD is 20 times that of a person who is the same age and does not receive dialysis.
- 8% CPR survival to hospital discharge



Carmen A. Patavino spent his last day watching his beloved golf on television and talking to visitors in brief sentences. Fatigue, not pain, marked his final hours.

Staff photo by MARK M. MURRAY

His decision to die

Editor's note: Soon after Carmen A. Patavino decided to stop kidney dialysis, he and his family and his doctor invited the Republican to observe his final hours in the hope that his decision will help others.

By PATRICIA NORRIS
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Death came quietly to Carmen A. Patavino.

Like a whisper trailing off into air, he closed his eyes.

It was the way he wanted it.

It was the way he chose to die. Like an increasing number of people, Patavino of Wilbraham decided to end his dialysis treatment and drift into a slumber-like peace.

He was 92. His family, seated by his bed, had not yet noticed he was gone.

"My dad was a very precise person. Everything was neat as a pin. His ending, his exit was as orderly and perfect," said his daughter, Emma Migdal of Wilbraham.

Patavino, normally a spry man with



Staff photo by MARK M. MURRAY

Golfing buddy Bob Droge of Scotia, N.Y., holds the hand of his long-time friend the day before Carmen Patavino died.

twinkling eyes, did not welcome his own death easily, however. The man with end-stage renal disease prayed actively for a miracle before he elected to stop dialysis and ultimately hasten his end.

“We’d been hoping he would come to this decision on his own.

My mother has been so tired, and we really feel like this is a gift he is giving us.”

Daughter Ann Vineola said shortly after her father decided to end dialysis

But after years on the machine that mechanically cleansed his blood three times a week, Patavino could no longer deny his small body was wearing out. The relief of coming home after treatment had been replaced by a fatigue so bone deep it almost always stopped him at his kitchen door. His wife of 63 years had to help him remove his jacket just so he could make it through the door.

Over the last decade, cessation of dialysis or withholding it altogether has become a more accepted option for people with end-stage renal disease. Although

Please see Dialysis, Page A22

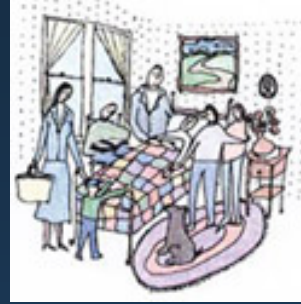


High discontinuation rate



- 32% in New England
- 25% in United States

Symptoms During Last 24 Hours Following Discontinuation (N=79)



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

All ESRD Deaths: Post Death Family Questionnaire (N=86)



Place of death	Hospital	57%
	Nursing Home	14%
	Home	27%
Was this the preferred place of death?	No	38%
	Yes	35%
	Not sure	27%
Was the death peaceful?	No	12%
	Yes	64%
	Not sure	24%

All ESRD Deaths: Post Death Family Questionnaire



Pain in the last week of life

Percentage of patients in pain	73.3%	
Frequency	All of the time	27.4%
	Most of the time	35.5%
	Half of the time	8.1%
	Occasionally	29.0%

All ESRD Deaths: Post Death Family Questionnaire



Pain in the last week of life

Percentage of patients in pain		73.3%
Severity	Extreme	35.6%
	Moderate	55.9%
	Not severe	8.5%
Distress level	Very much	59.7%
	Quite a bit	20.8%
	Somewhat	19.5%
Told family member about pain directly	Yes	70.7%
	No	29.3%

Barriers to the Provision of Hospice Services for ESRD Patients



- Financial disincentives
- Lack of patient awareness of life-limiting nature of ESRD resulting in many not wanting to discuss end-of-life issues
- Nephrologists and dialysis staff lack of familiarity with hospice
- Hospice providers lack of familiarity with ESRD patients and their issues

Who are the Nephrologists?

Fellowship Survey

Holley et al. Am J Kidney Dis 42(4):813-820, 2003.

- N=171
- Almost all in 2nd year of Nephrology Fellowship
- 73% characterized themselves as more inclined towards the technological and scientific, rather than the social and emotional aspects of medical care.



Fellows Exposure to Palliative Care

Holley et al.



	Geriatric	Critical Care	Nephrol.
Completed 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%

Fellowship Survey

Holley et al.



During your fellowship, were you explicitly taught to:





Lessons from the field: ESRD patients in hospice

Malene Davis, RN,MSN,MBA

Elements of a successful strategy



- Management considerations
- Developing criteria
- Developing service line
- Education
- Outreach
- Data
- Costs

Management considerations



- Open access
- Cost
- Counseling staff
- Staffing issues

Developing Criteria



- Is the renal problem the 'terminal' dx?
- Do other co-morbidities exist?
- Major symptoms
- Documentation
- Identifying patients

Building the bridge



- Transportation
- Team – community, health process

Medicare Hospice Benefit



- Covers core services – nurses, social workers, nursing assistants, chaplain
- DME, Rx, Supplies
- All related to the terminal illness
- Volunteers and Bereavement
- Per diem rate based on MSA

Education

- Renal physicians
- Health care professionals
- Community



Outreach

- Marketing strategy
- Dialysis providers
- Nephrologists



Data



- Team effort: Dialysis center and hospice
- Numbers in hospice
- Peritoneal dialysis
- Cost analysis
- Documentation issues

Costs



- Transportation
- Administration
- Dialysis costs
- Staffing issues

Case study



- Referral
- Patient and family assessment
- Goals for care
- Role of team members
- Interventions and outcomes

Summary/ Q&A



- Refer to list of resources for Promoting Excellence presentations
- Additional resources on the website www.promotingexcellence.org
- Questions for presenters