

Acceptance Doesn't Mean Giving Up

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Objectives

- Understand the importance of advance care planning
- Increase social work interventions for end of life care
- Gain confidence in working with patients, families and staff around end of life issues

V-Tag 457

- Subpart C, Patient Care 494.70
- (a) Patients' rights
 - (6) Be informed about his or her right to execute advance directives, and the facility's policy regarding advance directives
 - Requires the facility to inform patients about advance directives
 - The standard does not require that all patients have an advance directive

Advance Directives

- Written and completed by a competent person
- States an individual's preference
 - degree of medical care and treatment desired
 - specific wishes, values, goals; life experiences, cultural, religious views
 - (Living Will)
- Or stipulates decision maker
 - (Health Care Proxy; Medical Power of Attorney)
- Recognized by State law
- www.caringinfo.org

Do Not Resuscitate Order

- A physician's written order instructing healthcare providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest.
- A person with a valid DNR order will not be given CPR under these circumstances.
- Although the DNR order is written at the request of a person or his or her family, it must be signed by a physician to be valid.

Texas Out of Hospital DNR

- A non-hospital DNR order is written for individuals who are at home and do not want to receive CPR.
- www.dshs.state.tx.us/emstraumasystems/dnr.shtm

State Laws

- Texas has enacted a law requiring patients' advance directives and “do not resuscitate” (DNR) preferences to be honored
- Facilities are required to know and comply with such state laws

LIABILITY FOR FAILURE TO EFFECTUATE DIRECTIVE

- Sec. 166.045
- b) A physician, or a health professional acting under the direction of a physician, is subject to review and disciplinary action by the appropriate licensing board for failing to effectuate a qualified patient's directive in violation of this subchapter or other laws of this state

Medical Records

- V-Tag 730
 - (2) All clinical information pertaining to a patient must be centralized in the patient's record, including whether the patient has executed an advance directive

Phase 1: Initiation

Challenges:

Trauma
Disruption
Confusion
Fear

Phase 2: Chronic Fluctuating Illness

Challenges:

Chronicity/unpredictability
Regimen/modality change
Mood changes
Relationship stress
Grief
Commitment

Phase 3: Physical Decline + Death

Challenges:

Decline in physical functioning
Suffering/discomfort
Loss of control dependency
Caregiver Burnout
Hopelessness
Sadness/Despair



ADJUSTMENT TO CKD STAGE 5: A Disease Course Perspective

* See full page slide
at end of handout.

CNSW Outcomes Training Program

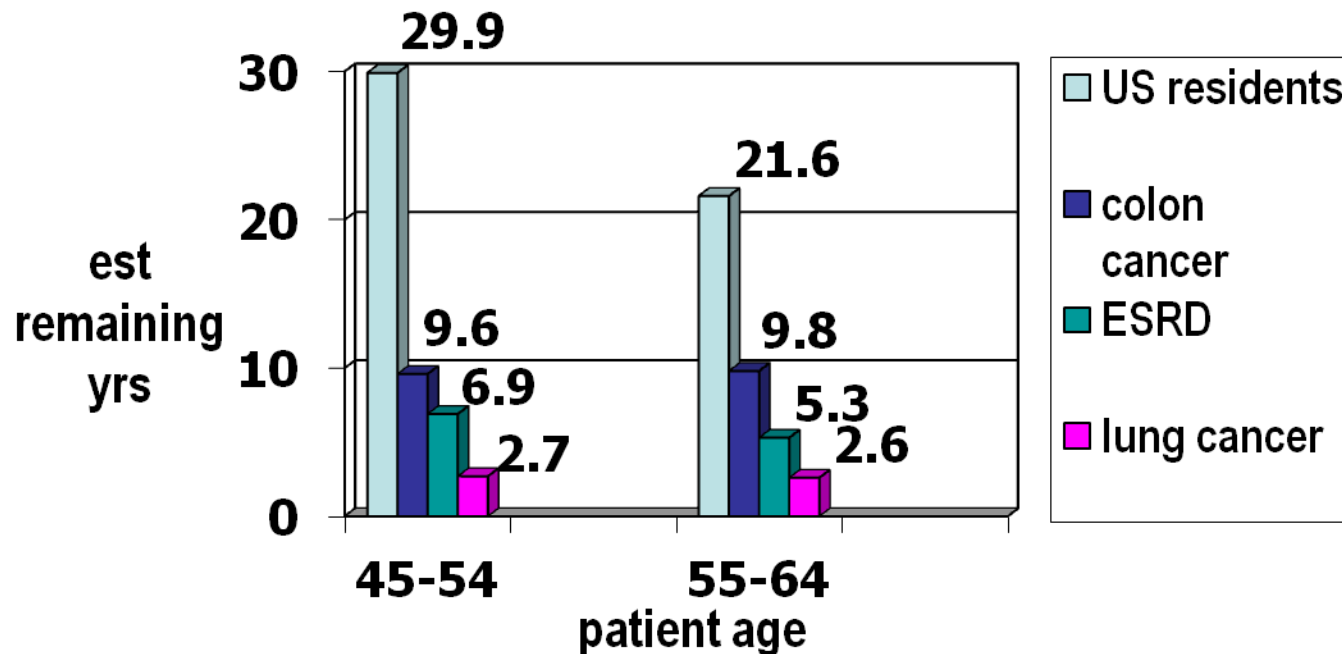
Phase III: Physical Decline and Death

Challenges

- Decline in physical functioning
- Suffering/discomfort
- Loss of control dependency
- Caregiver Burnout
- Hopelessness
- Sadness/Despair

Life Expectancy

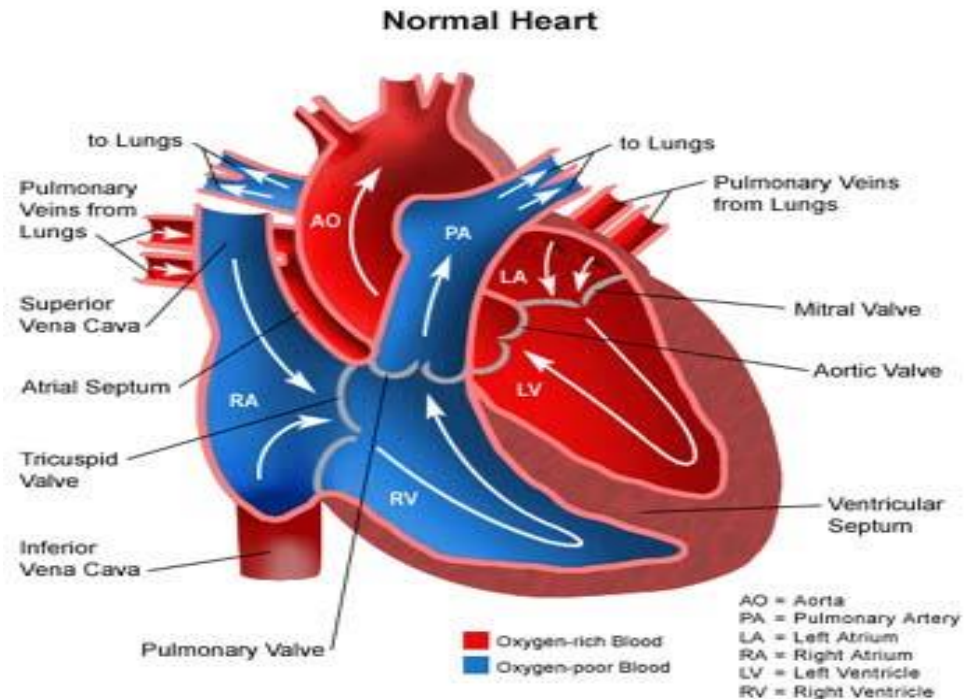
- Dialysis patients live one-fifth as long as age-matched patients who do not have kidney disease (USRDS)



Cardiovascular Disease and ESRD

- 50% of ESRD patients die of cardiovascular disease

◦ *Living Longer, Living Better, NKF*



Predictors for Poor Prognosis in ESRD Patients

- Age
 - Functional ability
 - Nutritional status
 - Comorbid conditions—DM, MI, DHF
-
- RPA/ASN, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, 2000

Profile of Who is More Likely to Withdraw from Dialysis

- white
- female
- diabetic
- isolated
- age
- lack significant other
- reside in SNF
- have physical pain or more co-morbidities
- recent experience of a medical complication or “failure to thrive”
- *low patient perceived quality of life*

Using the KDQOL in Advance Care Planning

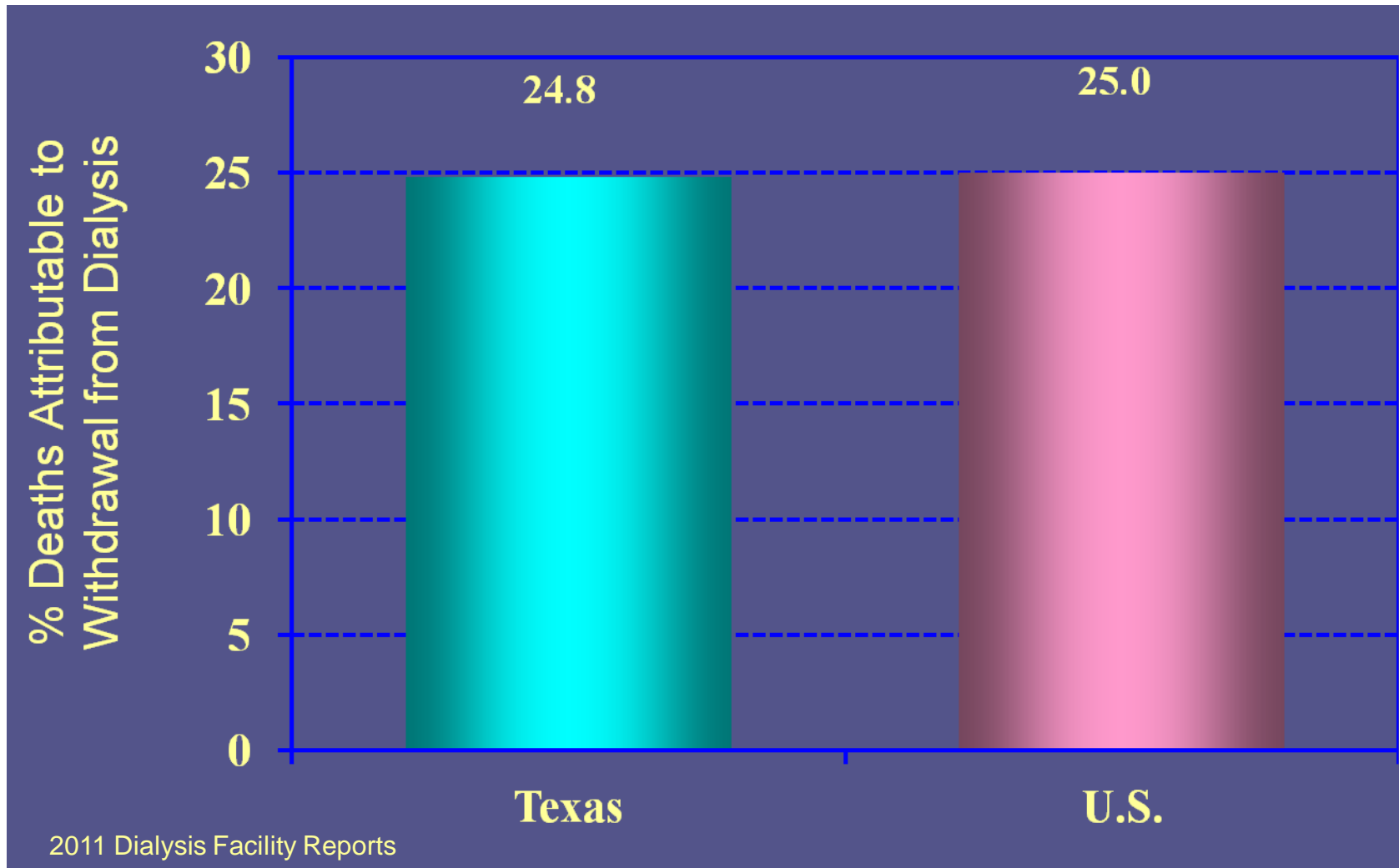
- Review scores of survey with patient
- If scores are low or significantly decreased from previous survey
 - Discuss how ESRD & treatment impact day to day life
 - Discuss patient's goals
 - Review treatment options, including no treatment
 - Review advance care planning

End of Life

- There are different trajectories of dying, depending on the underlying health status of the patient and the nature of the terminal illness
 - (IOM, 1997)
- The *meaning* that comes with end of life is different for each of us

2007-2010

Percent Total Deaths Attributable to Withdrawal from Dialysis



CPR vs. “Allow Natural Death”

- 87% of patients want CPR (*influence of TV*)
- 13% of patients don't want CPR even if arrest is caused by accident or drug reaction
- More than 3/4's of dialysis patients report
 - that they would want to stop dialysis in certain health states
 - permanent coma or severe dementia

▫ *(King and Moss) AJKD 38: 847-852, 2001*

What defines a “good” death experience?

- Opportunity to say goodbye
- Death at home if possible
- Opportunity to be present at time of death
- Knowledge that there is physical comfort
- Chance to complete important tasks
- Moral and emotional support before and during the death process
- Contact with nephrology social worker after death was considered helpful by 86% of participants

▫ Anne Woods, CNSW, 1999 (21 families from 5 N E clinics)

WHAT DO PATIENTS WANT?

- Talk in an honest and straightforward way
- Be willing to talk about dying
- Give bad news in a sensitive way
- Listen
- Encourage questions
- Know when it is the right time to discuss death and dying (when is the patient ready)
- Balance - leave room for hope

20 Focus groups, 137 subjects
(Arch Int Med 26 March, 2001)

Jean Holley, MD
www.kidneyeol.org

- Advance care planning is not piece of paper, *it's a dialogue.*

- The Caregivers Path to Compassionate Decision Making.

- Vicki Kind

Phase III:

Physical Decline and Death

Adjustment Goals

- Acceptance of Decline (KDQOL)
- Physical Comfort
- Patient Direction of Care
- Care Management
- Emotional Endurance
- Peace/Integrity

Representative Questions for End-of-Life Discussions

- Goals –
 - What are your biggest fears?
 - What are your most important hopes?
 - Is it more important to you to live as long as possible, despite some suffering,
 - or to live without suffering but for a shorter time?
 - Given the severity of your illness, what is most important for you to achieve?

Quill, 2001

Representative Questions for End-of-Life Discussions

- Values
 - What makes life most worth living for you?
 - Are there any circumstances under which you would not find life worth living?
 - What do you consider your quality of life to be like now?
 - Have you seen or been with someone who had a particularly good (or difficult) death?

Quill, 2001

Representative Questions for End-of-Life Discussions

- DNR Orders
 - If you were to die suddenly, that is, you stopped breathing or your heart stopped, we could try to revive you by using CPR.
 - Are you familiar with CPR?
 - Have you given any thought as to whether you would want it?

Quill, 2001

The Surprise Question

- “Would I be surprised if this patient died in the next year?”
 - useful tool for nephrologists
 - to identify dialysis patients who have a much greater risk of dying within the next year
 - to identify candidates for a discussion about ***advance care planning***

Moss A., et. al. 2008

Phase III:

Social Work Interventions

- Psycho-education (ambivalence, etc)
- Support (patient-directed)
- End of life decisions
- Acknowledge patient current fears
- Life review
- Family closure and preparation
- Supporting the team

Phase III Interventions with Pediatric Population

- Stay close during physical deterioration, each change can be a traumatic event.
- Help parents sort out their ambivalence and feelings toward this stage
- Give parents support while they live in “limbo”
- Expect some anger at the medical system for not being able to do more
- Help parents prepare other children for loss

- *If You Choose Not to Start Dialysis Treatment*

- answers general questions about not starting dialysis

- *When Stopping Dialysis Treatment is Your Choice: A Guide for Patients and Their Families*

- answers commonly-asked questions about dialysis withdrawal

Palliative Care

- To palliate means to make comfortable by treating a person's symptoms from an illness.
- Palliative care may be given at any time during a person's illness, from diagnosis on
- The goals of palliative care are to improve the quality of a seriously ill person's life and to support that person and their family during and after treatment.

▫ www.caringinfo.org (website of National Hospice & Palliative Care Organization)

Hospice

- Hospice focuses on relieving symptoms and supporting patients with a life expectancy of months not years, and their families
- Hospices have a set of defined services, team members and rules and regulations
- Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations
- Relies on the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so

Hospice, Medicare & ESRD

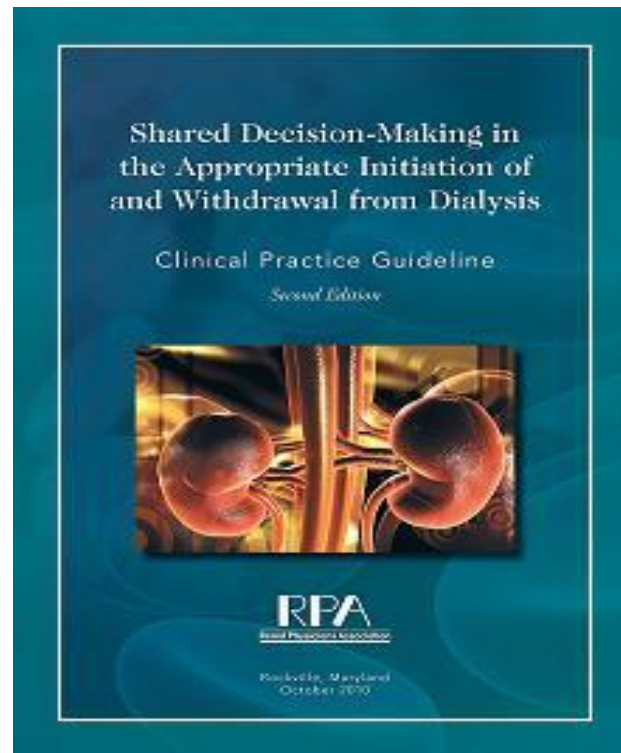
- Dual diagnosis
- Work to establish a relationship with a hospice agency and educate them in what to expect if a patient withdraws from treatment
- Provide inservice to team prior to a patient's desire to withdraw from dialysis so they can be prepared to support the patient

Provide Staff Support

- Staff change of focus
 - From life sustaining to palliative
- Staff may identify patient's end of life process with their own personal experiences
 - PTSD
 - Grief
- Teach and model how to say goodbye
 - We may have to examine our own previous losses

- www.kidneyeol.org
 - Has links to state advance directive forms
- www.promotingexcellence.org
 - Research and recommendations from RWJ Foundation's study of ESRD patients

Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis, RPA



Shared Decision Making Toolkit

- General Checklist for Implementing Shared Decision-Making Recommendations
 - Depression
 - Cognitive capacity
 - Decision making capacity
 - Prognosis tools
 - Preparation for dying checklist
 - Pain and symptom assessment & management

Phase III:

Outcome Measurement

- Scale patient sense of comfort
- Scale patient/family perception of support/care management
- Measure team's response to social work inservice (comfort with emotional aspects with end of life care)

Personal Stories

- [The Shadow of Your Smile](#) details the end-of-life story of dialysis patient Jerry Eilers, as told by his wife and caretaker Denise Eilers, RN, BSN
- [The Last Lecture](#), Randy Pausch
 - “Show gratitude. Gratitude is a simple but powerful thing.”

Small but Important Words in Finding Peace

- I'm sorry
- I forgive you
- I love you

- “To be cliché, death is a part of life and it’s going to happen to all of us. I have the blessing of getting a little bit of advance notice and I am able to optimize my use of time down the home stretch.”

- Randy Pausch, [The Last Lecture](#)

References

- The Advance Care Planning Policy is a template to assist dialysis facility staff in developing advance care planning policies and procedures. <http://www.kidneyeol.org/Advance-Care-Planning/For-Professionals.aspx>
- The **POLST** Form is a standardized form designed to convert wishes for life-sustaining treatments into medical orders. It was created to ensure that treatment wishes are honored in the event that a patient/resident is unable to speak for himself or herself. Surrogate decision makers may communicate treatment preferences on behalf of incapacitated individuals so the form can be used for those who lack decisional capacity. http://www.kidneyeol.org/Files/POLST_Form.aspx
- Quill TE, Arnold RM, Platt F. “I wish things were different”: expressing wishes in response to loss, futility, and unrealistic hopes. *Ann Intern Med* 2001;135(7): 551-5.

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- Moss A., et. al. Utility of the “Surprise” Question to Identify Dialysis Patients with High Mortality. Clin J Am Soc Nephrol, 2008;3:1379-1384
- Buckman, Robert MD, Modified from version: Sandrick, K. “Codified principles enhance physician/patient communication.” Bulletin of the American College of Surgeons, 83(11): 13-17, 1998.
- Woods, A, Berzoff, J. Cohen, L, Cait, C, Pekow, P, German, M & Poppel, D. The Family Perspective of End-of-Life Care in End Stage Renal Disease: The Role of the Social Worker, Journal of Nephrology Social Work, 1999, Vol. 19.

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