Differing Perspectives: Providing End-of-Life Care to a Diverse Patient Population

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Objectives

- Indicate the changing US demographics
- Identify cultural/ethnic differences in communication & end-of-life decision-making
- Illustrate strategy to elicit preferred communication approach for different cultures
- Introduce the second edition of the RPA clinical practice guideline on dialysis decision-making

A 70 year-old Chinese woman now living in the US has worsening leg edema. Her daughter-in-law is her primary caregiver and medical power of attorney. The patient's understanding of English is limited, and her family members, who speak to her in Chinese, say that she occasionally appears to be confused because she tells them that she has no pain or shortness of breath, but her grimacing and panting suggest otherwise. While living in China, the patient had taken a dietary supplement containing aristolochic acid, which caused CKD. The supplement was stopped, but the patient's CKD continued to progress slowly. At the time, the patient confided to the family, "I can deal with anything, as long as I know I won't need dialysis." Accordingly, the family tells her the leg swelling is due to getting older, and they decline further blood testing and consideration of dialysis.

Which of the following is the most appropriate next step in communication with this patient and family?

A. Speak to the patient alone with the assistance of a Chinese interpreter.
B. Study the Chinese culture to learn how to proceed with decision-making.
C. Follow the family's wishes without further discussion with the patient.
D. Discuss how decisions should be made and by whom with the patient and the family.

US Ethnicity Now and 2050

Ethnicity	2005	2050
White	69%	53%
African American	13%	12%
Hispanic	13%	25%
Asian	4%	8%

Smelser NJ, Wilson WJ, Mitchell F. America Becoming: Racial Trends and Their Consequences, Volume 1. Washington, DC. National Academies Press, 2001.

Culture fundamentally shapes the way people make meaning out of illness, suffering, and dying, and therefore also influences how they make use of medical services at the end of life…Failure to take culture seriously means we elevate our own values and fail to understand the value systems held by those of different backgrounds.

Kagawa-Singer M and Blackhall, LJ. Negotiating Cross-Cultural Issues at the End of Life: "You Got to Go Where He Lives". JAMA. 2001; 286:2993-3001.

Cultural Competence involves recognizing …

- one's own cultural biases and understanding each patient's and family's preference for information sharing and decision making
- different degrees of truth telling
- preferences for patient-centered vs family-centered styles of decision making
- preferences for more paternalistic or collaborative styles to inform choice.

Quill TE , Holloway RG, Shah M, et. al. Primer of Palliative Care, 5th ed. American Academy of Hospice and Palliative Medicine, 2010.

Assuming a Chinese woman would not want to be told her diagnosis because she is Chinese is **stereotyping**. Insisting that she *must* be told, even at the risk of violating her wishes, is a form of **cultural imperialism**.

Kagawa-Singer M and Blackhall, LJ. Negotiating Cross-Cultural Issues at the End of Life: "You Got to Go Where He Lives". JAMA. 2001; 286:2993-3001.

The clinical encounter often requires a negotiation between the world views or cultures of the clinician and the patient/ family to reach mutually acceptable goals. In the end, addressing and respecting cultural differences will likely increase trust, leading to better clinical outcomes and more satisfactory care for patients and their families.

Kagawa-Singer M and Blackhall, LJ. Negotiating Cross-Cultural Issues at the End of Life: "You Got to Go Where He Lives". JAMA. 2001; 286:2993-3001.

Withdrawing from Dialysis

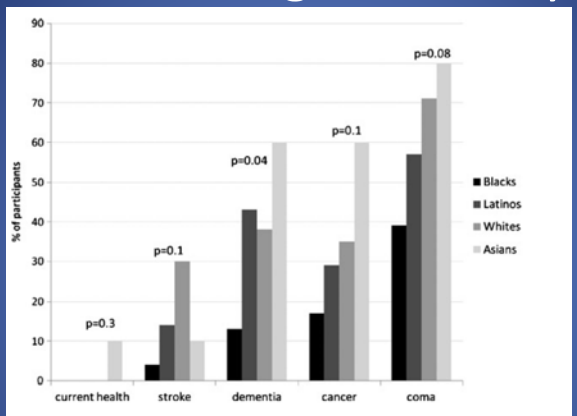

Fig. 2. Proportion of participants ($N = 61$) who would probably or definitely withdraw from dialysis in different health states, by race/ethnicity. *P*-values are for comparison across race/ethnicity groups. $N = 23$ for Blacks, $N = 7$ for Latinos, $N = 21$ for Whites and $N = 10$ for Asians.

Tamura MK, et al. Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients. *Nephrol Dial Transplant* 2010;25:237-42.

Advance Care Planning

Table 3. Proportion of participants engaging in steps of advance care planning by age and race/ethnicity groups ($N = 61$)

Characteristic	End-of-life discussion % (N)	Advance directive % (N)	DNR/DNI order % (N)
Overall	57 (35)	38 (23)	10 (6)
Age			
<50 years ($N = 11$)	64 (7)	18 (2)	0 (0)
50–75 years ($N = 37$)	57 (21)	41 (15)	11 (4)
>75 years ($N = 13$)	54 (7)	46 (6)	15 (2)
P-value	0.9	0.3	0.5
Race			
Black ($N = 23$)	70 (16)	30 (7)	0 (0)
Latino ($N = 7$)	29 (2)	14 (1)	0 (0)
White ($N = 28$)	38 (8)	43 (9)	24 (5)
Asian ($N = 10$)	90 (9)	60 (6)	10 (1)
P-value	0.01	0.2	0.05

DNR/DNI—do not resuscitate or do not intubate.

Tamura MK, et al. Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients. *Nephrol Dial Transplant* 2010;25:237-42.

Racial Preferences Regarding CPR

Table 1. Demographics of Subject Population and Preferences Regarding CPR

Demographic	All Subjects (n = 469)	Subjects on Dialysis		P
		Wanting CPR	Not Wanting CPR	
Participants (%)	—	87	13	—
Mean age (y)	60 ± 16	59 ± 16	69 ± 12	0.002
Duration of dialysis (y)	3.3 ± 3.9	3.3 ± 3.8	3.0 ± 3.8	NS
Education (y)	12.4 ± 2.9	12.4 ± 2.8	12.1 ± 3.3	NS
Men (%)	46	88	12	—
Women (%)	54	86	14	—
White (%)	63	81	19	—
Black (%)	34	97	3	<0.001*
No. of comorbid conditions	1.6	1.5	2.0	0.016
Have living will (%)	45	43	61	0.01
Live in nursing home (%)	4	3	9	0.017
Widowed (%)	22	20	36	0.026

Abbreviation: NS, not significant.
*Compared with white variable data.

At any age, blacks were more likely to want to be resuscitated than whites (adjusted OR, 6.56; 95% CI, 2.57 to 22.27).

Moss AH, et al. Attitudes of patients toward cardiopulmonary resuscitation in the dialysis unit. *Am J Kidney Dis* 2001;38(4):847-52.

Japanese Patients' Preferences for Receiving CPR and Continuing Dialysis

Table 2. Dialysis Patients' Preferences for Receiving CPR and Continuation of Dialysis Treatment: Response

	Yes	Uncertain	No
Preference for receiving CPR			
In the current health status	42 (37-47)	14 (11-17)	44 (39-49)
If they were demented	12 (9-15)	11 (8-14)	77 (73-81)
If they had a terminal cancer	12 (9-15)	11 (8-14)	77 (73-81)
Preference for continuing dialysis			
If they were demented	18 (14-22)	22 (18-26)	60 (55-65)
If they had a terminal cancer	45 (40-50)	18 (14-22)	36 (31-41)

NOTE. Values expressed as percent (95% confidence interval). N = 398.

Miura Y, et al. Dialysis patients' preferences regarding cardiopulmonary resuscitation and withdrawal of dialysis in Japan. *Am J Kidney Dis* 2001;37:1216-22.

Racial Differences in the use of Advance Directives in Hospice

"Compared to Whites, African Americans were less likely to have completed an advance directive and had less favorable beliefs about hospice care (both $P<.001$)… However, when all of these factors were combined (Hospice Beliefs, Preferences for Care, Spirituality, Healthcare System Distrust, and Beliefs about Dying), race was no longer a significant predictor of either of the two outcomes. Our findings suggest that ethnicity is a marker of common cultural beliefs and values which in combination influence decision-making at the end of life."

Johnson KS, et al. What explains racial differences in the use of advance directives and attitudes toward hospice care? *J Am Geriatr Soc* 2008;56(10):1953-8.

Cultural Variation in Communication

- Communication of bad news
- Locus of decision-making
- Advance planning for terminal illness

Culturally Sensitive Physician-Patient Communication

- Cultural context is key
- In low-context cultures communication is usually direct and words are relatively unambiguous (e.g. Americans)
- In higher-context cultures communication may be primarily non-verbal (e.g. Asian and Native American)

Communicating Bad News: Cultural Differences

Family members may actively protect terminally ill patients from knowing their condition in…

- Hispanic communities
- Chinese communities
- Pakistani communities
- Italian communities

Reasons for Non-Disclosure of Terminal Illness

- Discussion of serious illness may be viewed as disrespectful or impolite
- Discussion of serious illness is viewed as provoking unnecessary patient depression or anxiety
- Direct disclosure may eliminate family hope of recovery
- Speaking the name of a life-threatening condition may make death in terminal illness a reality

Locus of Decision-Making

- Family versus individual decision-making
  - Koreans
  - Mexican Americans
- Physician-centered paternalistic decision making
  - Eastern European Cultures
  - Russian Patients
  - East Asian Cultures
  - Pakistani Cultures

Domains of Cultural Competence

- Cultural Competence
  - Rationale
  - Context
  - Definition
- Epidemiology and Disparities in Health
- Understanding the Impact of Stereotyping
  - Bias
  - Discrimination
  - Racism
- Factors Influencing Health Disparities
- Cross-Cultural Clinical Skills

Potential Solutions for Cross-Cultural Differences in Decision-Making Values

- **Physicians should become knowledgeable about cultural norms in patients they commonly treat.**
- Physicians must find accessible, culturally trained translators.
- Untrained translators should be briefly oriented to their role.
- Physicians can ask patients their preferences for communication.

Cross-Cultural Interview Questions

- "Some people want to know everything about their condition, others prefer that doctors talks mainly to their family. How do you prefer to get this information?"

Cross-Cultural Interview Questions

- “Do you prefer to make medical decisions about future tests or treatments for yourself, or would you prefer that someone else make them for you? If so, whom?”

Cross-Cultural Interview Questions

- “Is there anything that would be helpful for me to know about how your family/community/religious faith views serious illnesses and treatment?”

Cross-Cultural Interview Questions

- "Sometimes people are uncomfortable discussing these issues with their doctor who is of different race, cultural background, or sex. Are you comfortable with me treating you? Will you please let me know if there is anything about your background that would be helpful for me to know in working with you or your family member?"

Patients Who Request that the Physician Discuss their Condition with Family Members

- "Would you be more comfortable if I spoke with your brother (son, etc.) alone or would you like to be present?"
- If the patient chooses not to be present, offer, "If you change your mind at any time and would like more information, please let me know. I will answer any questions that you have."

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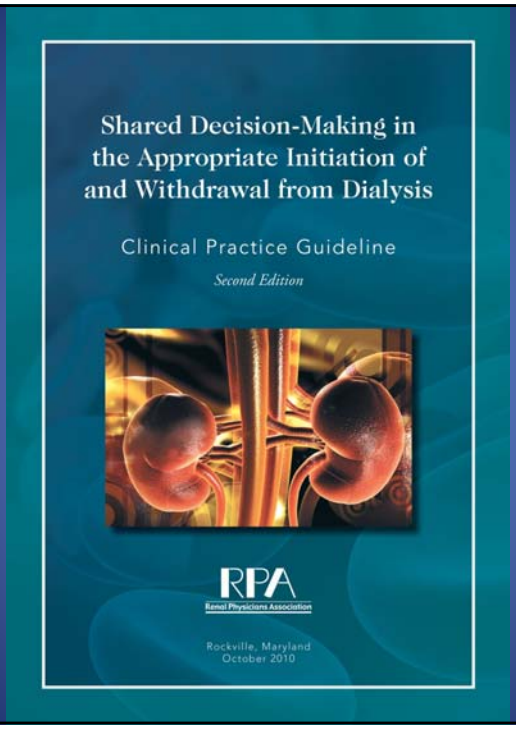
Review

- We need to be sensitive to the fact that not all persons or groups desire information or make decisions in the same way we do.
- We need to establish the preferred means of communication.
- We need to ask how much people want to know and to whom they want information given.
- Use of a cultural translator to help with patients from another culture is recommended.



General Checklist Regarding Shared Decision-Making Recommendations

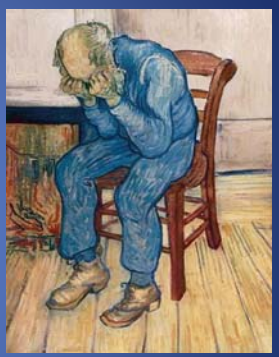
The Working Group developed the following checklist that gives examples of items that could be added to the Comprehensive Assessment and Plan of Care to monitor implementation of shared decision-making recommendations.

o yes	o no	Patient has been screened for depression.
o yes	o no	Patient score indicates possible depression.
o yes	o N/A	If screened positive, patient has been referred for possible treatment.
o yes	o no	Patient has been screened for mental status.
o yes	o no	Patient score indicates possible cognitive impairment.
o yes	o N/A	If cognitive impairment is indicated, have potentially reversible contributors been ruled out?
o yes	o no	Patient has been assessed for decision-making capacity.
o yes	o no	Patient's preference for a legal agent has been elicited.
o yes	o no	Patient or designated legal agent has been provided information on advance directives. Date: _____ Staff: _____
o yes	o no	Patient has signed durable power of attorney for health care on chart.
o yes	o no	Patient has signed living will in chart.
o yes	o no	Patient has completed a Physicians Orders for Life-Sustaining Treatment (POLST) Paradigm form.
o yes	o no	Circumstances, if any, under which patient would desire discontinuation of dialysis have
o yes	o no	Circumstances, if any, under which patient would not want CPR, mechanical ventilation, or tube feeding
o yes	o no	Patient or designated legal agent has been provided prognostic information. Estimated survival prognosis is a range of _____ to _____ (state months or years) based on :_____ (e.g., table, model, clinician)
o yes	o no	Present and projected future quality of life and/or functional status has been discussed. If assessed, instrument used _____, score: _____, date: _____.
o yes	o NA	Has an intervention been planned to improve quality of life or functional status?

Informing Patients: Recommendation No. 3:
All patients with AKI, stage 5 CKD or ESRD should receive patient-specific estimates of prognosis.

2 or more → Poor prognosis[1,2,3]

1. ≥ 75 years
2. High comorbidity scores ("No" to "Surprise" Question)
   - A. (e.g., modified Charlson Comorbidity score ≥ 8)
3. Marked functional impairment
   - A. (e.g., Karnofsky performance status score < 40)
4. Severe chronic malnutrition
   - A. (e.g., serum albumin level < 2.5 g/dL using the bromcresol green method).



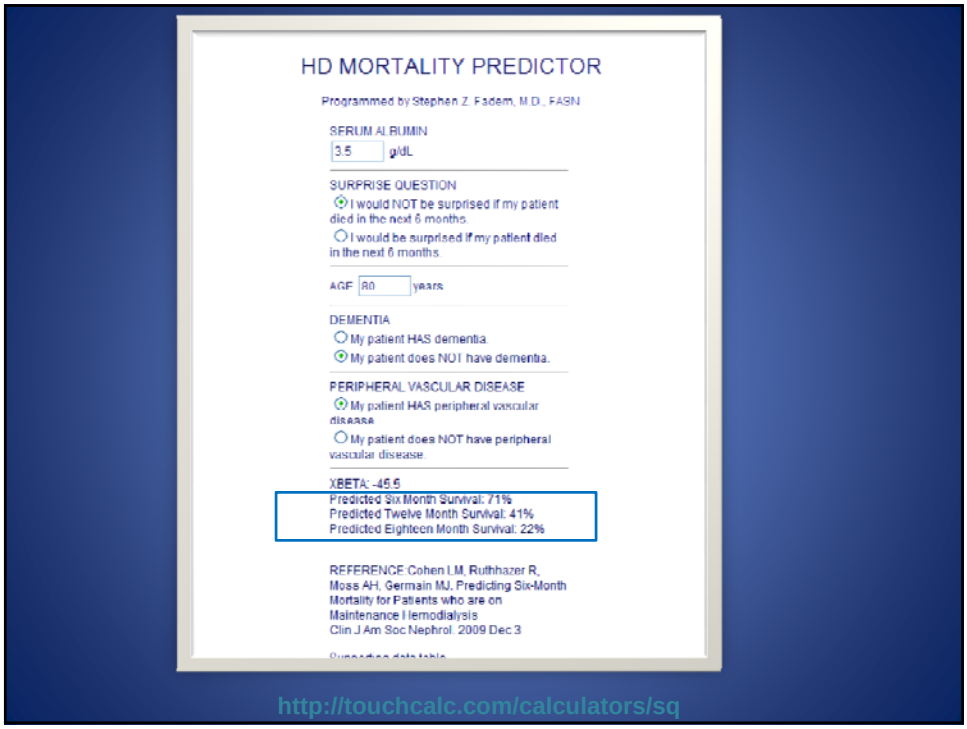
Patients in this population should be informed:

1. Dialysis may not confer a survival advantage or improve functional status over medical management without dialysis
2. Dialysis entails significant burdens which may detract from their quality of life.

[1] Arnold RM, Zeidel ML. Dialysis in frail elders--a role for palliative care. N Engl J Med 2009;361(16):1597-8.

[2] Murtagh FE, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. Nephrol Dial Transplant 2007;22(7):1955-62.

[3] Halstenberg WK, Goormastic M, Paganini EP. Validity of four models for predicting outcome in critically ill acute renal failure patients. Clin Nephrol 1997;47(2):81-6.



http://touchcalc.com/calculators/sq

Informed Consent for Elderly CKD Patients SHOULD INCLUDE:

Dialysis may not confer a survival advantage

- **Patients with this level of illness more likely to die than live long enough to progress to ESRD** [1]
- **The majority of patients in their condition die or succumb to significant functional decline during their first year on dialysis** [2]

[1] J Am Soc Nephrol 2007;18(10):2758-2765.
[2] J Am Soc Nephrol 2003;14(4):1012-21.

Life on dialysis entails burdens likely to detract from their quality of life

- **Surgery and complications for vascular access or peritoneal access placement**
- **Adverse physical symptoms on dialysis --dizziness, fatigue, and cramping, and a feeling of "unwellness" after dialysis.**
- **Travel time and expense to and from dialysis**
- **Long hours spent on dialysis → reduction in the time available for physical activity.**

Unnecessary "medicalization of death"

- **Invasive tests, procedures, and hospitalizations.**

KIDNEY END-OF-LIFE COALITION

For additional information, including resources for patients and families, visit **www.kidneyeol.org**

- Advance care planning information
- Do not resuscitate orders in the dialysis unit
- Access to hospice
- Clinician educational resources

Contact the Kidney End of Life Coalition at **kidneyeol@nw5.esrd.net**