

Role of Patient Education in Dialysis Modality Selection

Fredric O. Finkelstein
Yale University
New Haven, CT

Patient-Centered Care Shared Decision Making

The new “buzz” words in health care delivery and reform

Focus on the individual patients and their concerns, values, and goals

The clinician’s role changes:
to focusing on providing information and education to patients so they can make informed decisions about available treatment options

taking into account the various therapeutic approaches that are available in the context of the individual’s values, goals and objectives

UK Health Care Reforms

Roland, Rosen: NEJM 364:1360, 2011
Faden, Chalkidou: NEJM 364:1289, 2011

- “No decision about me without me.”
- Patient choice is emphasized with a focus on outcomes– in terms of education and treatment – outcomes that matter to patients

Bipartisan Policy Center Health Care Cost Containment Initiative: Recommendations

(Daschle, Domenici, Frist, Rivlin, NEJM 369:471, 2013)

Prioritize, consolidate, and improve the use of quality measures by consumers and practitioners...Quality metrics must ... provide the meaningful data needed for patients and families to make informed choices... (these metrics will need to be) understandable and accessible to consumers. ”

Patients as “Consumers” Paul Krugman: NY Times 4/22/11

- How did it become accepted to refer to patients as consumers?
- “Medical care is an area in which crucial decisions – life and death– must be made ... And these decisions.. require a vast amount of specialized knowledge.”
- “The idea ... that doctors are just providers selling services to health care consumers is sickening... a sign that something has gone very wrong... with our society’s values.”

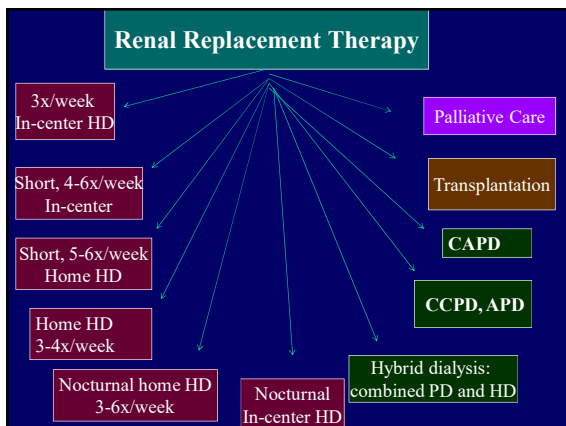
In other words, we cannot ignore doing what is fundamentally right for the patient ...yet we must also acknowledge, address and understand individual patient perceptions and preferences

Baron and Davis, NEJM 1/9/14
Accelerating The Adoption Of High-value Primary Care:
Milestones to be Achieved

- Assessments and improvements in patient experience
- Shared decision making, including use of decision aids
- Participation in a learning community and sharing of knowledge and tools
- Meaningful use of health information technology

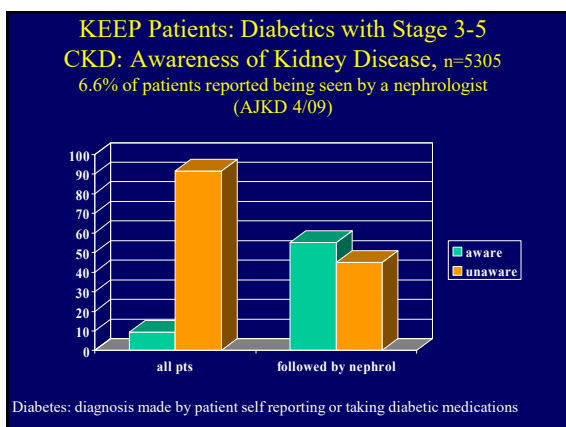
How Does This Apply to CKD
Education?

The Conventional, Default
Position of 3x/Week In-Center
HD Is No Longer the Standard of
Care



Realities in the Current World of CKD/ESRD Education

- The majority of CKD patients report not knowing they have kidney disease
- CKD patients seeing nephrologists know surprisingly little about CKD or ESRD treatment options
- Discrepancy between what patients perceive and want and what health care providers think they perceive and want



% of CKD Patients Seen in CKD Clinics With No Knowledge of Various ESRD Therapies: 7 Sites in Canada and US, n=708, (Finkelstein et al: Kidney Int, 74:1178-84, 2008)

No knowledge of HD	43%
No knowledge of CAPD	57%
No knowledge of APD	66%
No knowledge of transplantation	56%
No knowledge of Any modality	35%

**Revamping CKD Education:
Defining The Problems**

- Defining the target: *CKD pre-dialysis (as well as ESRD patients once stable after they start dialysis)*
- Understanding the value: *patient centered care*
- Recognizing the challenges: *communication and literacy problems*
- Reformatting the process: *provide information that patients can understand and be responsive to individual patient's needs*

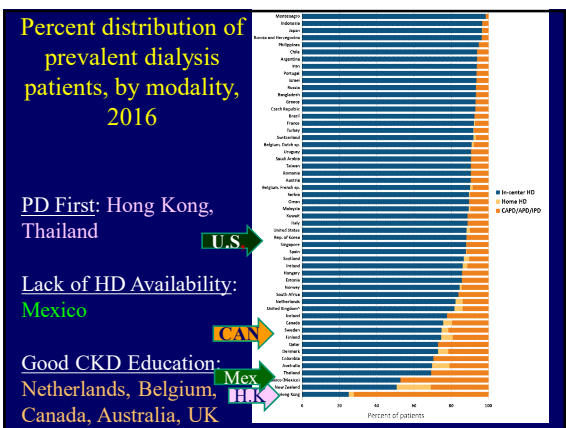
Reformatting What We Do

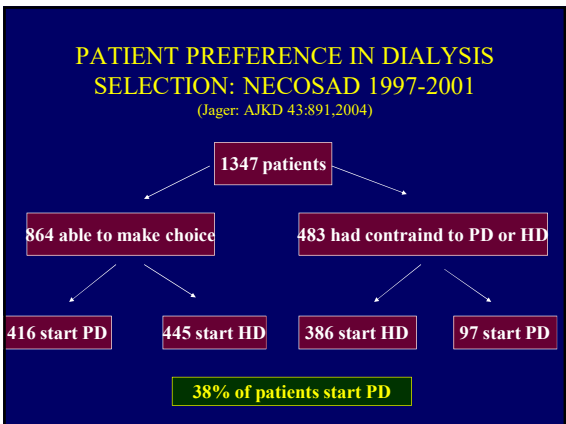
- Team approach to education: *physicians, nurse clinicians, physician assistants, nurses, technicians, peers*
- Written material, web based education
- Multiple educational activities: *written material, web sites, individual sessions, group sessions, peer support*
- Motivational interviewing

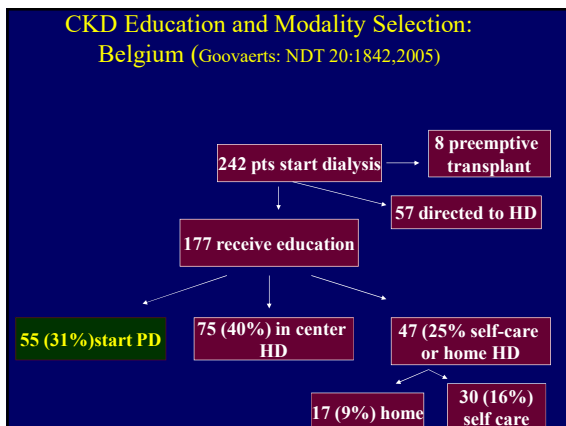
Research Needs to be Done to Better Understand How Information is Best Provided to Patients

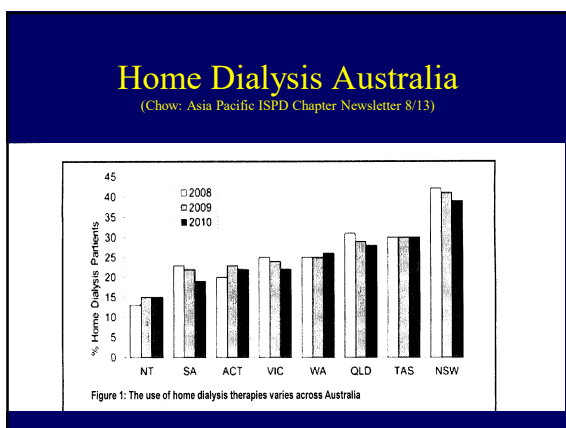
What Is Happening Globally?

Variable PD Utilization







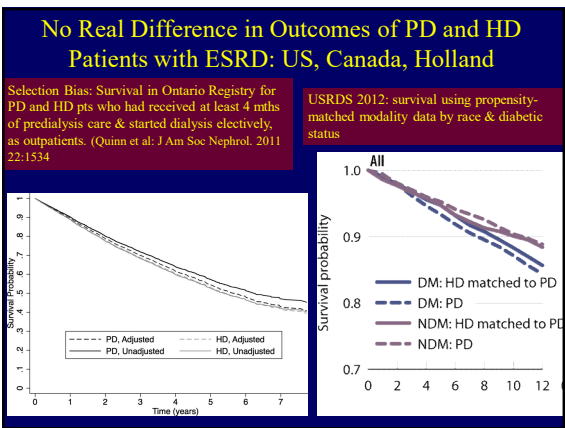


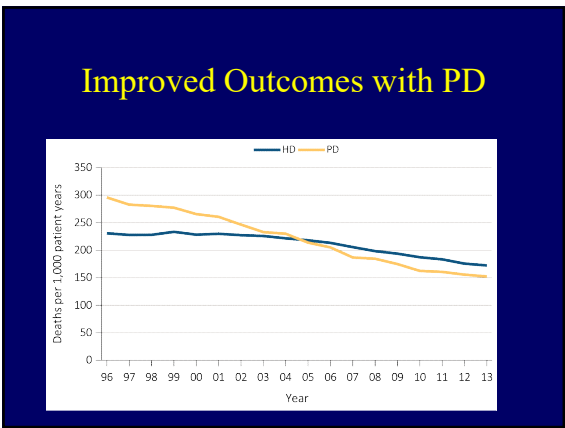
- Satellite Dialysis, California:
75.5% center HD, 22% on PD, 2.5% on Home HD
- New Haven Home Dialysis:
77% center HD, 20% on PD, 3.0% on Home HD
- Wake Forest, North Carolina:
74% center HD, 20% on PD, 6 % Home HD
- Ontario (whole province):
76% center HD, 20% on PD, 4 % on Home HD
- Western Australia
75% center HD, 22% on PD, 3% on Home HD

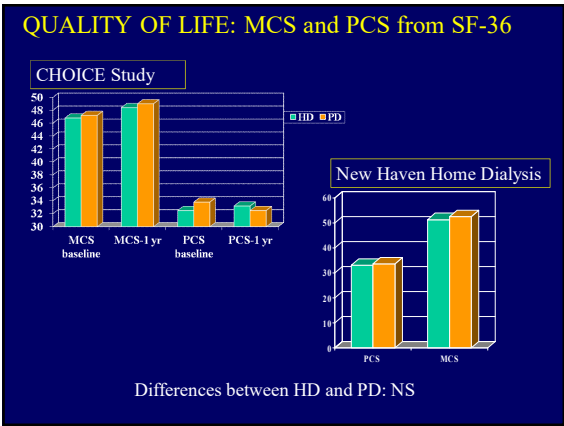
What Do We Tell Patients About PD Compared to HD?

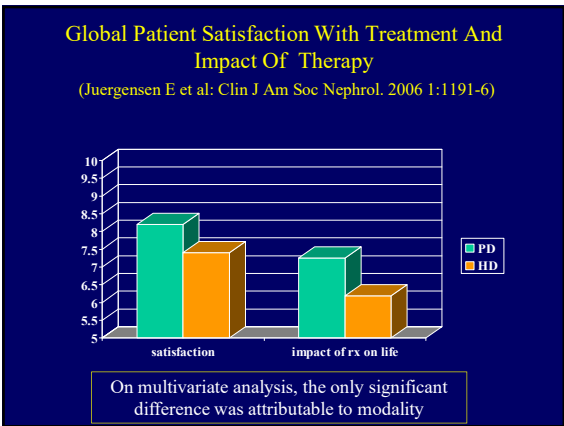
Are the Outcomes Different?

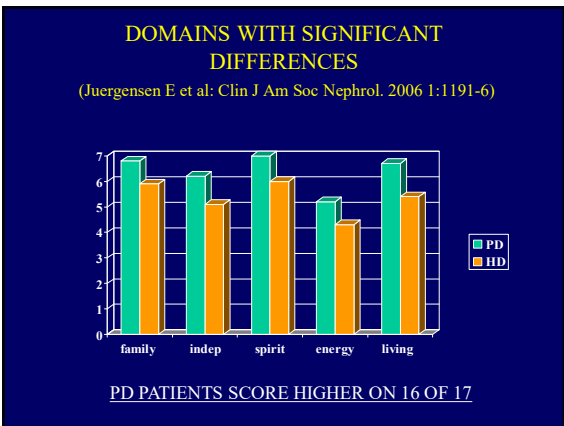
What About Impact on Quality of Life?

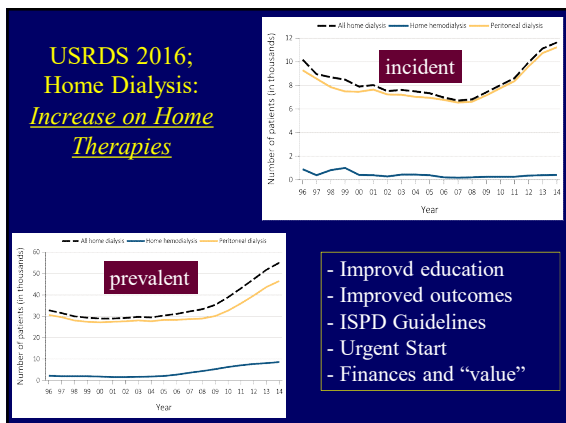


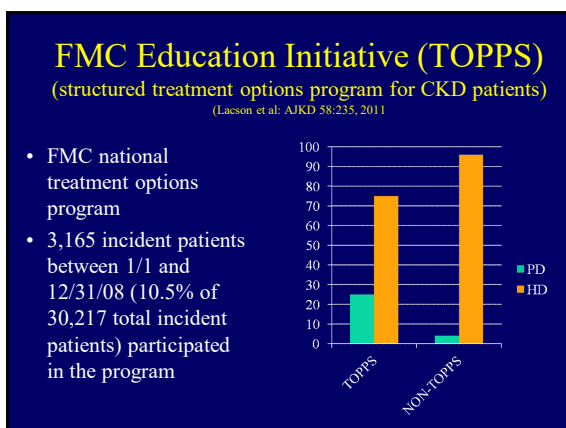






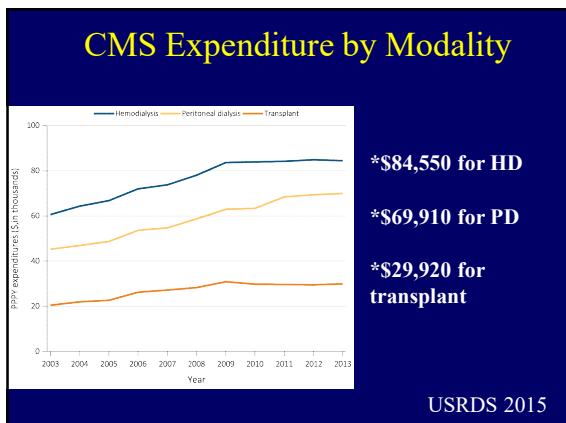






Urgent Start Approach Globally

- Ontario, Canada *Perit Dial Int.* 2016 36(2):171-176
- Saudi Arabia *Perit Dial Int.* 2014 34(2):204-11
- USA *Adv Perit Dial.* 2014;30:36-9.
- Brazil *Int Urol Nephrol.* 2016 Feb 20
- Denmark *Perit Dial Int.* 2015 Nov;35(6):622-4
- Saving Young Lives Program *Kidney Int.* 2016 89:254-6. 13 programs in low resource settings (Africa and SE Asia)



- ### New Haven
- Monthly CKD classes
 - One-on-one sessions with nurses, physician assistants
 - Revamping written material –modification of the Yorkshire Decision Aide
 - Revamping on-line educational material
 - Expand nursing home programs for PD
 - Explore assisted PD

- ### What Are The Gaps?
- What are the best educational materials?
 - Challenges of literacy
 - Harnessing new technologies? Access to computers?
 - Losing track of patients who have been started on HD in hospital
 - PD in the elderly
 - Home support – *assisted PD*
