

Patient Centered Care:  
*The Patient Experience*

*How To Incorporate This Into Routine Patient Care*

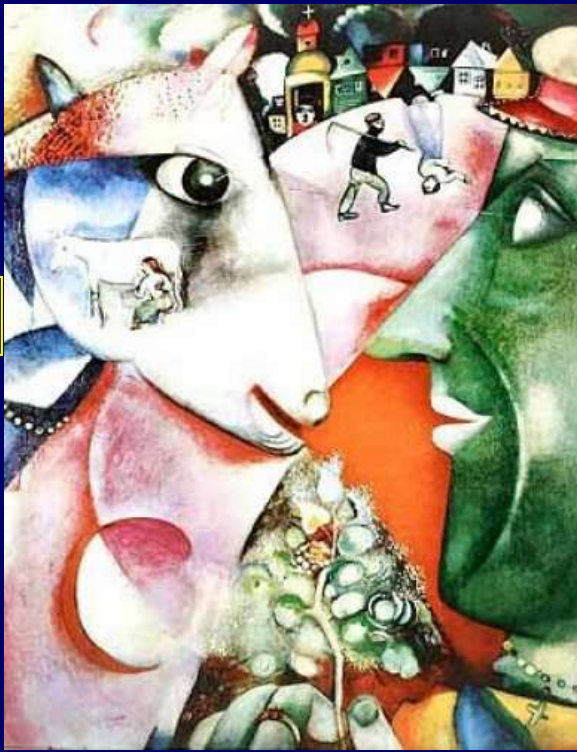
Fredric Finkelstein

Clinical Professor of Medicine

Yale University, New Haven, CT

# Each Person's Experience is Unique

Michael Kimmelman: NY Times 6/16/11 “Art is not just about what’s great or famous...It’s a mirror we hold up that looks different to everyone who sees it, and whose beauty lies in us and our capacity to dream...”



Chagall



Malevich

Eric Kandel, the Nobel Prize neuroscientist in the book *The Age of Insight*, notes that we need to understand that each individual, because of unconscious and conscious processes, sees the same painting (or experiences the same event) differently, uniquely interpreted by his or her brain.

# Pablo Picasso

“There is no abstract art. You must always start with something. Afterward you can remove all traces of reality.”

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# 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*

# Recent Reassessment of the Importance of PROMs and HRQOL for Nephrology

- Series of papers in CJASN—November, 2017
- Major focus in the U.S., UK, etc  
*--mandated by the government to assess HRQOL*
- K/DIGO conference – January, 2018
- ISPD guidelines 2018: *Redefinition of goals of assessing adequacy of PD therapy*

# K/DIGO Meeting Madrid, January, 2018

- Reassessment of goals of ESKD care
- Shift to recognize that primary goal of treatment is to understand, identify, and try to meet individual patient goals and objectives
- Provide basic level of ESKD care, including “dose” of dialysis, anemia management, etc
- But, look at these in the context of the individual patient’s experience

# ISPD Guidelines for High Quality Dialysis

- Requirement to assess HRQOL, focusing attention on these assessments
- Amount of dialysis delivered: *redefinition of  $KT/V$*
- Volume control
- Limiting dextrose exposure: *to minimize the stimulation of inflammatory markers*



# How Then Do We Begin to Understand Patient Perceptions:

*Utilization of Patient Reported Outcomes Measures (PROMs) and Their Incorporation into Routine Patient Care*

# Definitions

(from FDA position paper on PROs, 2010)

([www.fda.gov/downloads/Drugs/Guidances/UCM193282](http://www.fda.gov/downloads/Drugs/Guidances/UCM193282))

- Patient Reported Outcome Measures (PROMs): measurements based on a report that comes directly from the patient about the status of a subject's health condition without interpretation by a clinician
- PROMs represent aspects of how patients function or feel related to a health condition or its treatment
- Goal of a PROM: enable us to measure the effect of a medical intervention on a patient

# PROS INFORM US ABOUT PATIENTS' PERCEPTION OF THEIR QUALITY OF LIFE

Quality of Life: (WHO Definition): “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”

Health Related Quality of Life: the extent to which one’s usual or expected physical, social, or emotional well being (*quality of life*) is affected by a medical condition or its treatment.

**PHYSICAL COMPONENT**

**Health Status  
Overall health**

**PSYCHOLOGICAL COMP**

**Emotional and interpersonal  
functioning**

**OVERALL HEALTH  
RELATED QUALITY  
OF LIFE**

**THERAPY COMPONENT**

**Impact of therapy on overall  
status  
Satisfaction with care**

**SOCIAL COMPONENT**

**Social functioning**

**In the context of the social and cultural environment in which one lives**

# TYPES OF QUALITY OF LIFE INSTRUMENTS

- Generic instruments: developed for use in the general population with a variety of diseases (*SF-36, Health Utility Index, EQ5D*) – cover a variety of domains
- Disease specific: focus on symptoms related to the specific disease or its interventions (e.g. KDQofL)
- Symptom specific: focus on specific symptoms produced by or associated with a particular disease/condition/therapy
  - Depression: Beck Depression Inventory, CES-D, PHQ9
  - Time to recovery after a hemodialysis session
  - Energy, vitality: domain of SF36, FACT-fatigue scale

All 3 instruments are important: Generic outcomes capture patients' more global experience while disease and symptom specific outcomes capture domains related to a specific condition or treatment intervention

# Examples of PROMs Used in Clinical Studies with ESKD

## General Questionnaires

KDQOL-36

KDQOL-SF

EQ5D

Choice Health Experience Questionnaire (CHEQ)

Dialysis Symptom Index

## Depression and Anxiety Screening:

Beck Depression Inventory

Patient health questionnaire 9

Center for Epidemiologic Studies Depression Scale

Hospital anxiety and depression score

## Caregiver Burden:

Zarit Burden Interview

# Domains of concern for the ESRD Patient

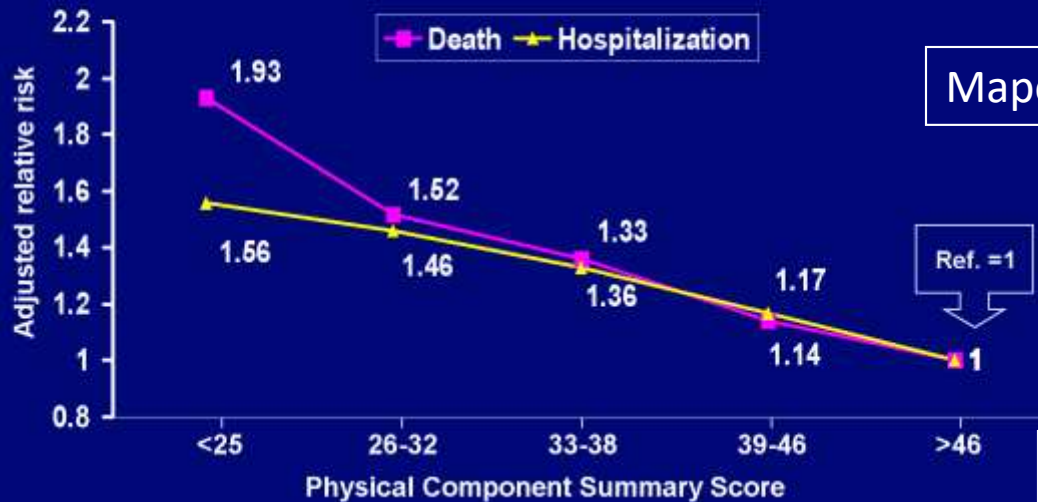
- Cognitive dysfunction
- Family and marital discord
- Depression
- Anxiety
- Fatigue
- Lethargy
- Physical functioning
- Sexual dysfunction
- Symptoms of neuropathy
- Sleep disturbances
- Uremic pruritus
- Anorexia, nausea
- Restless legs
- Satisfaction with dialysis treatment regimen
- Impact of the treatment regimen on their life
- Satisfaction with care provided
- Caregiver burden
- Appetite, abdominal discomfort, nausea, vomiting
- Additional physical symptoms

# Why Should Nephrology Be Interested In Focusing on HRQOL and PROs?

- The focus of health care delivery is changing
- Nephrology has lagged far behind other specialties in developing a patient centered approach incorporating PROMs into direct care
- Association of PROMs with mortality and hospitalizations
- Discordance between provider and patient perceptions of health status

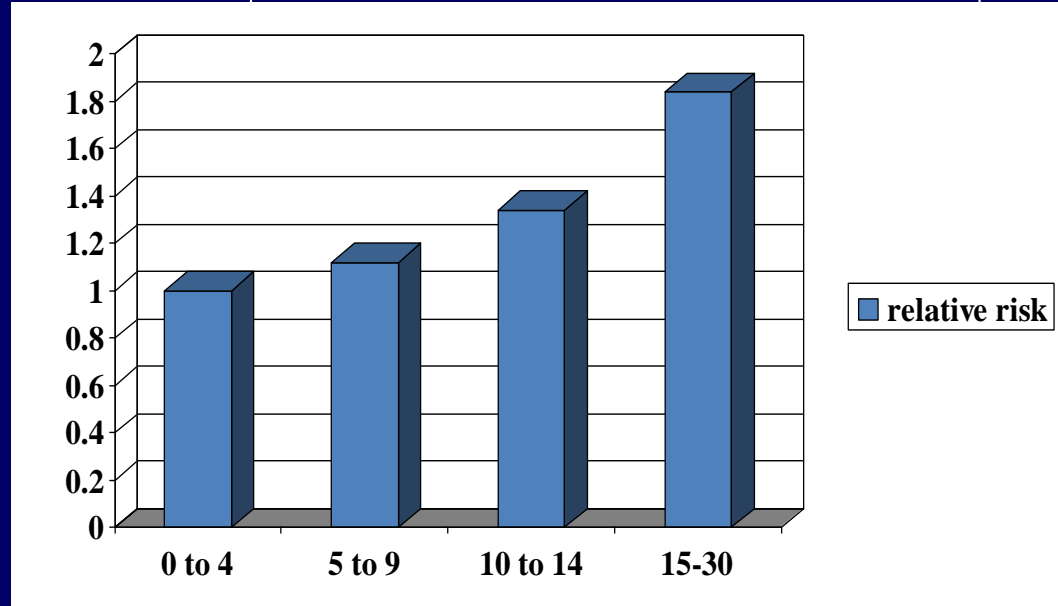


# Adjusted Relative Risk of Death and Hospitalization by Physical Component Summary Score, with Adjustment for Albumin



Mapes et al KI 64:339,2003

CES D scores and mortality n=9382  
Lopes: KI. 66:2047, 2004



# Provider Recognition of Symptoms of HD Patients

(Weisbord: CJASN: 2:960, 2007)

symptom	sensitivity
SOB	52%
Nausea	50%
Headache	25%
Vomiting	25%
Muscle cramps	17%
Feeling sad	17%
Dry skin	10%
Feeling anxious	6%
↓ interest in sex	6%

Questions were asked on the same day of patient and provider concerning sx present in the preceding 7 days

Sensitivity: proportion of pts with sx correctly identified by provider as having the sx

# Summary of Discrepancies Between CKD/ESRD Patients' and Providers' Reporting of Symptoms, Global QoL, General Health and Depression

Data from New Haven; presented at ASN 2016

<u>DIFFERENCE IN NET GENERAL SYMPTOM SCORE</u>	<u>n</u>
Different (>5)	<u>94</u>
Same (<5)	<u>99</u>
	<b>193</b>

<u>DIFFERENCE IN GENERAL HEALTH</u>	<u>n</u>
SAME	<u>72</u>
DIFFERENT (>1)	<u>120</u>
	<b>192</b>

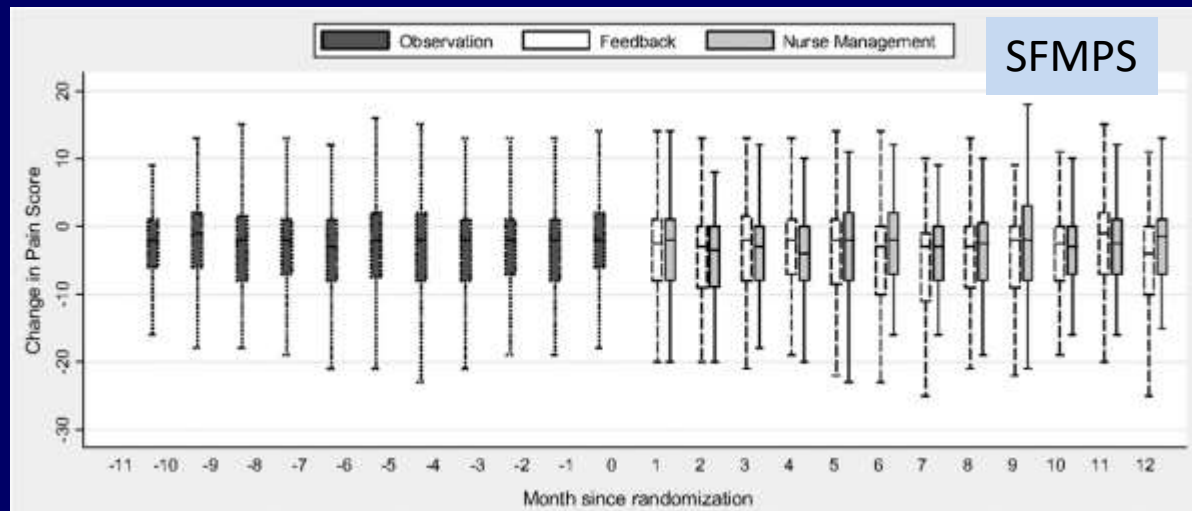
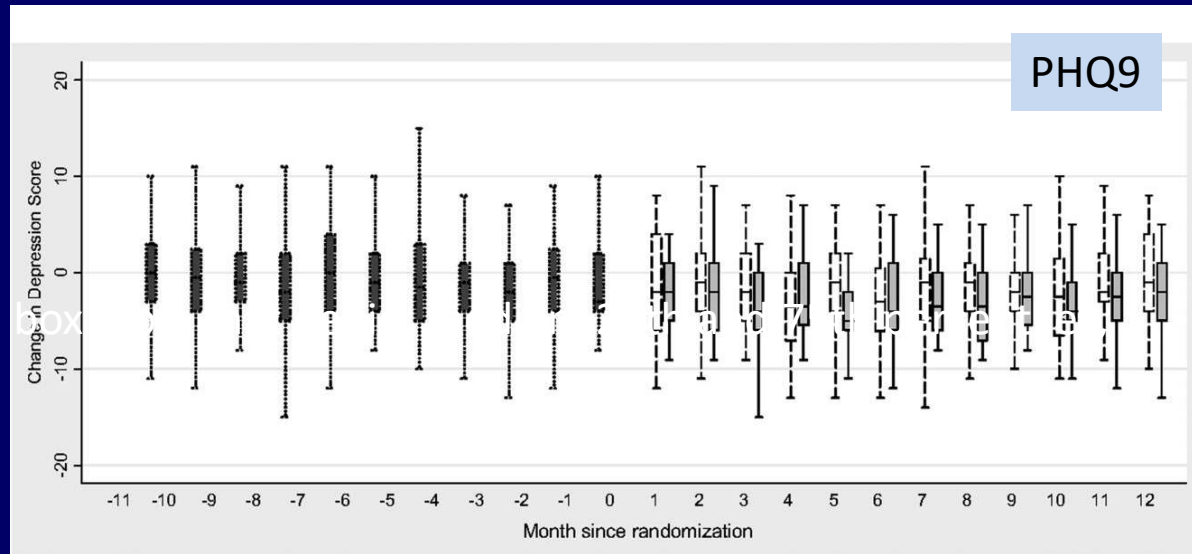
<u>DIFFERENCE IN GLOBAL QOL SCORE</u>	<u>n</u>
Different $\geq 2$	<u>82</u>
Same $\leq 1$	<u>106</u>
	<b>188</b>

	<u>PHQ2 SCORE</u>	<u>n</u>	
	SAME	<u>97</u>	
	DIFFERENT	<u>95</u>	
		<b>192</b>	

# Challenges of Incorporating PROMs Into Standard Care

- Problem in capturing an individual patient's experiences
- Appreciate the burdens on patients of completing PROMs and on providers of processing PROMs
- Variability in results over time in individual patients

# Longitudinal change in depression (PHQ9) and pain scores (Short Form McGill Pain Score) Weisbord et al. CJASN 2013;8:90-99



# Lessons From Other Specialties

- **Orthopedics:** assessing results of surgical interventions
- **Gynecology:** routine assessment of post-operative care
- **Neurology:** routine assessment using both generic and disease specific instruments
- **Oncology:** electronic testing
- **Psychiatry:** computer adaptive testing (CAT)

# Making Patients and Doctors Happy – *The Potential of Patient Reported Outcomes*

*Rotenstein et al NEJM 377:14, 2017*

- Dartmouth-Hitchcock Med Center: used PRO for clinical activities and research since 1998; patients surveyed reported that incorporation of PROs led to positive changes in their visits
- University of Rochester introduced a core set of PROs in 2015 which are now used in shared decision making in 30 university departments
- Mass General introduced PROs in 2012 and has collected 1.2 million PRO scores in 75 clinics across 21 specialties; this resulted in improved physician satisfaction, improved communication between patient and doctor, enhanced shared decision, and enhanced work flow efficiency

# Oncology

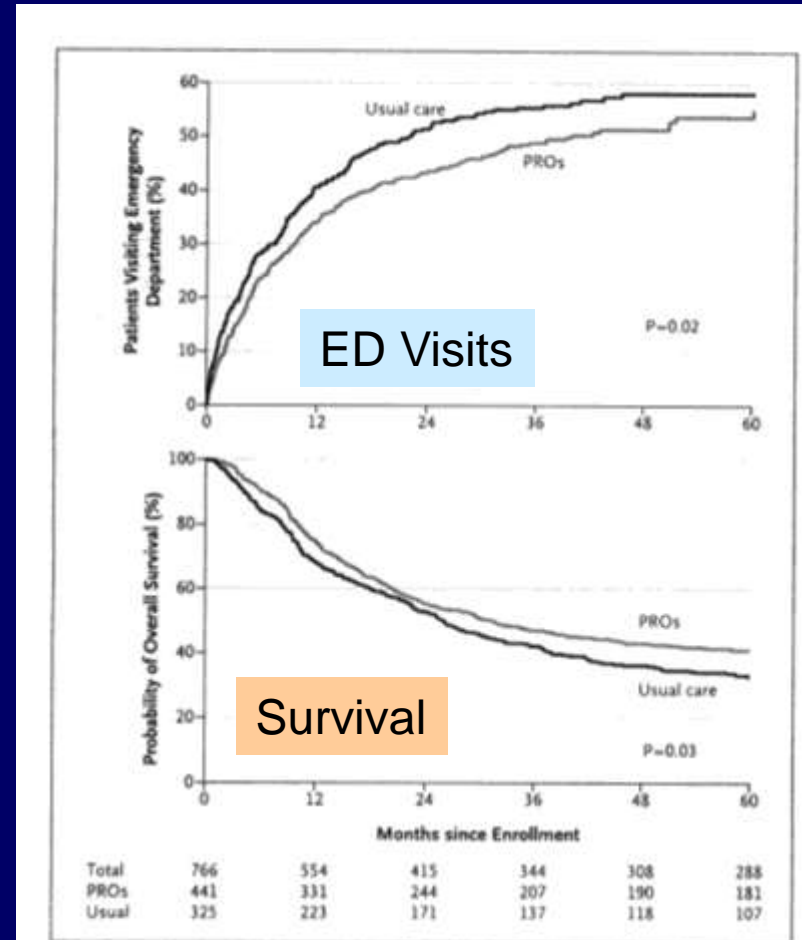
*(Basch: Patient-Reported Outcomes - Harnessing Patients' Voices to Improve Clinical Care. NEJM, 2017 12;376(2):105-108)*

- Routine use of PROMs: enhances the patients' and the clinicians' experience.
- For patients undergoing chemotherapy, treatment value cannot be summarized in an individual metric -- a multifaceted approach is necessary focusing on what is important to the individual patient
- The use of electronic testing has been shown of benefit in 3 domains:
  - a) informing clinicians of patients' perception of symptoms and quality of life.*
  - b) providing feedback to patients about how to inform clinicians about the presence of symptoms*
  - c) having a positive impact on "hard" outcomes, such as emergency department visits and hospitalizations.*



# Electronic PROMS in Oncology

*randomized trial (n= 766) of pts receiving chemotherapy-- assigned to usual care or electronically reported symptoms with alerts of severe or worsening symptoms sent to the health care team; resulted in lower mortality rates, improved quality of life, and reduced emergency department visits (Basch: NEJM, 2017).*



**Emergency Department Visits and Probability of Survival Associated with Integrating Patient-Reported Outcomes (PROs) into Cancer Care.**

Analysis of a randomized, controlled trial reveals that among 766 patients receiving chemotherapy and assigned either to usual care or to regularly reporting common symptoms over the Internet with automated alerts e-mailed to their nurses for severe or worsening symptoms, the PRO intervention was associated with significantly fewer emergency department visits and improved overall survival, as well as improvements in quality of life. Nurses responded to patients reports of symptoms with clinical actions such as telephone advice and new prescriptions in 76% of cases.<sup>1</sup>

## Psychiatry: Computerized Adaptive Testing (CAT)

- CAT can diagnose a major depressive disorder, anxiety disorder, bipolar disorder with a high sensitivity and specificity
- There is a 50-90% reduction in the number of items that need to be administered with no significant change in diagnostic accuracy.
- It can be repeatedly administered without response set bias
- CAT has been used to monitor patients with psychiatric illness over time with alerts sent to health care providers

# CAT (*Computerized Adaptive Testing in Nephrology*)

- We have developed a computer adapted program administered on an iPad, tablet or iPhone for CKD and ESKD patients
- Questions adapt to patient responses, enabling us to address a wide range of symptoms rapidly
- Results are printed out at time of clinic visit

But What Do We Do With The  
PROMS Once We Have Obtained  
Them????

This Is Indeed a Challenge

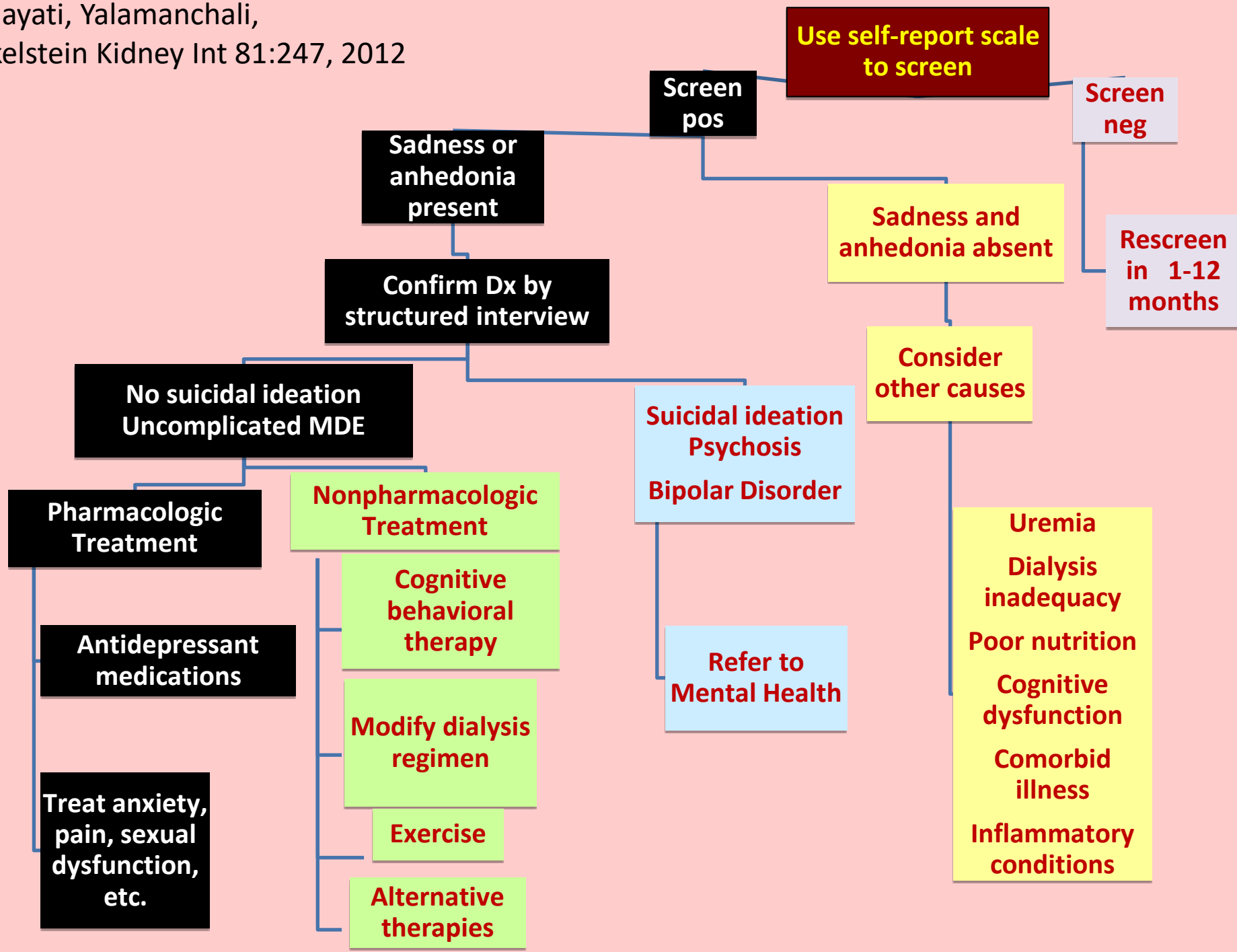
# Issues to Consider

- Make sure the problem area identified on testing is recognized by the patient as being important to him/her
- What are the treatment options for problem areas identified?
- What are the hazards of treating the area of difficulty?

# Sexual Activity in Women on HD

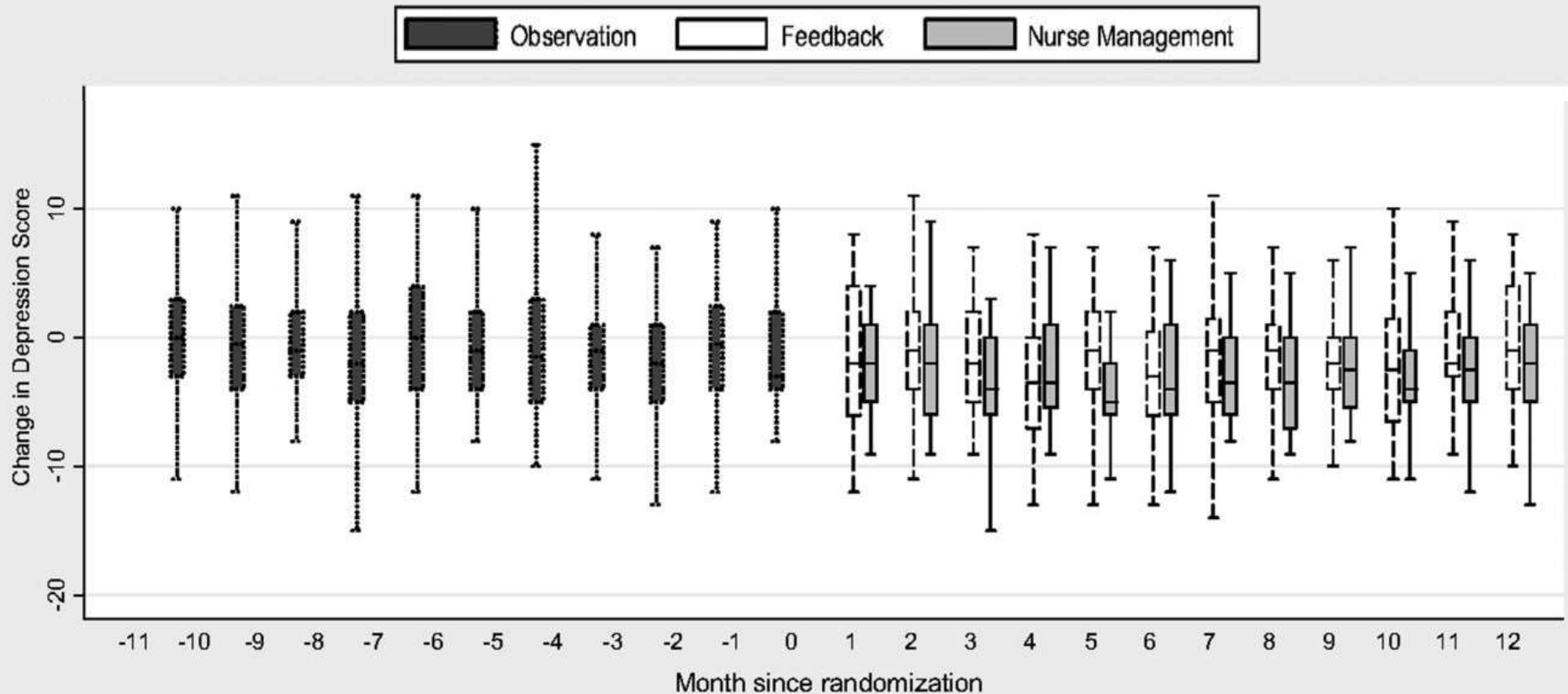
Mor et al CJASN 2014 9:128-34

- “Although many women receiving chronic hemodialysis are sexually inactive, few describe sexual difficulty. Most, including those with a lack of interest in sex, are satisfied with their sexual life and few wish to learn about treatment options. These findings suggest that true sexual dysfunction is uncommon in this population and that treatment opportunities are rare.”



Longitudinal change in depression scores (PHQ9) Weisbord et al. CJASN 2013;8:90-99

Nurse managers formulated pharmacologic and/or nonpharmacologic treatment recommendations based on well developed treatment algorithms and clinical judgment (Weisbord et al. CJASN 2013;8:90-99)





# Recommendations

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- Mandate that PROMs be incorporated into routine patient care, addressing some or all of the issues discussed
- Leave the mode and frequency of administration (paper, electronic, CAT) and the instruments to be used to the discretion of the facility
- Encourage innovative approaches given the lack of clear data on how PROMs should be incorporated into routine care and translated into improved patient experiences
- Require that there be documentation that domains of individual patient concerns have been acknowledged and that a plan to address these concerns has been noted. Plans could include addressing the problem using facility resources or making referrals to other health care providers or community resources.