

# D P P S

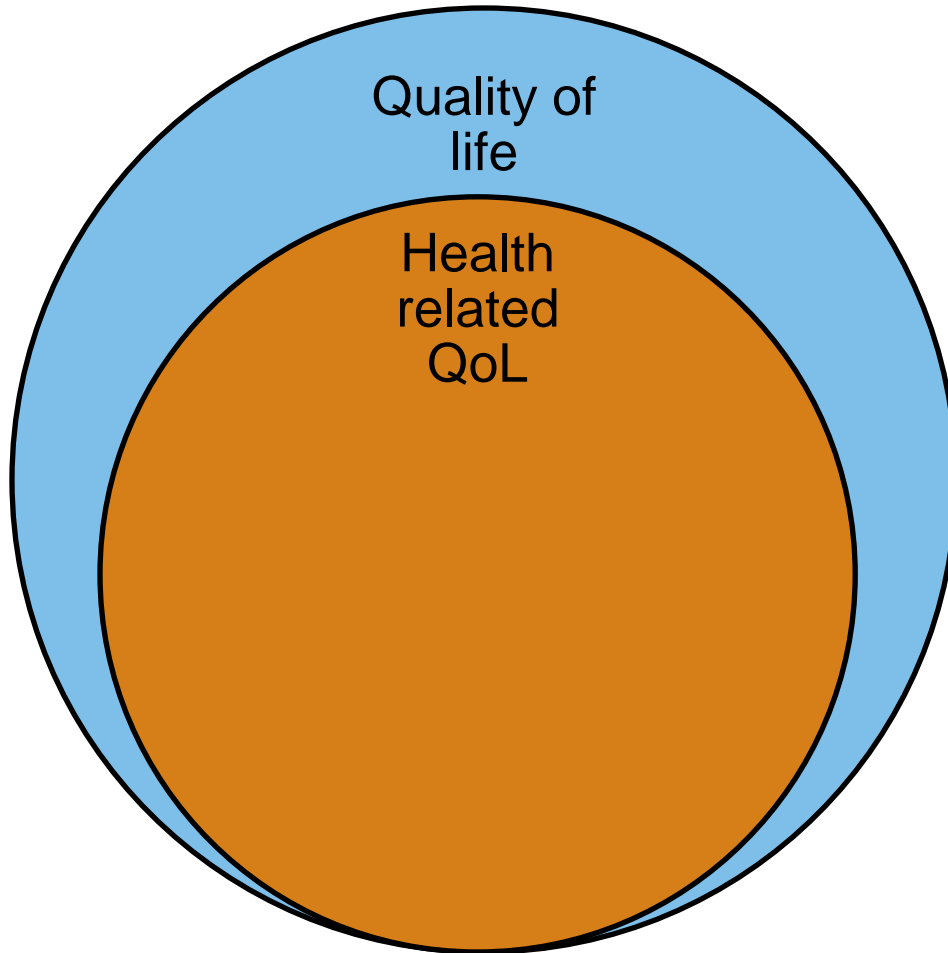
DIALYSIS OUTCOMES AND  
PRACTICE PATTERNS STUDY

**Ask your patients  
and do something about it:  
The patient experience in DOPPS**

**Jeanette Wallin**

EDTNA 2017

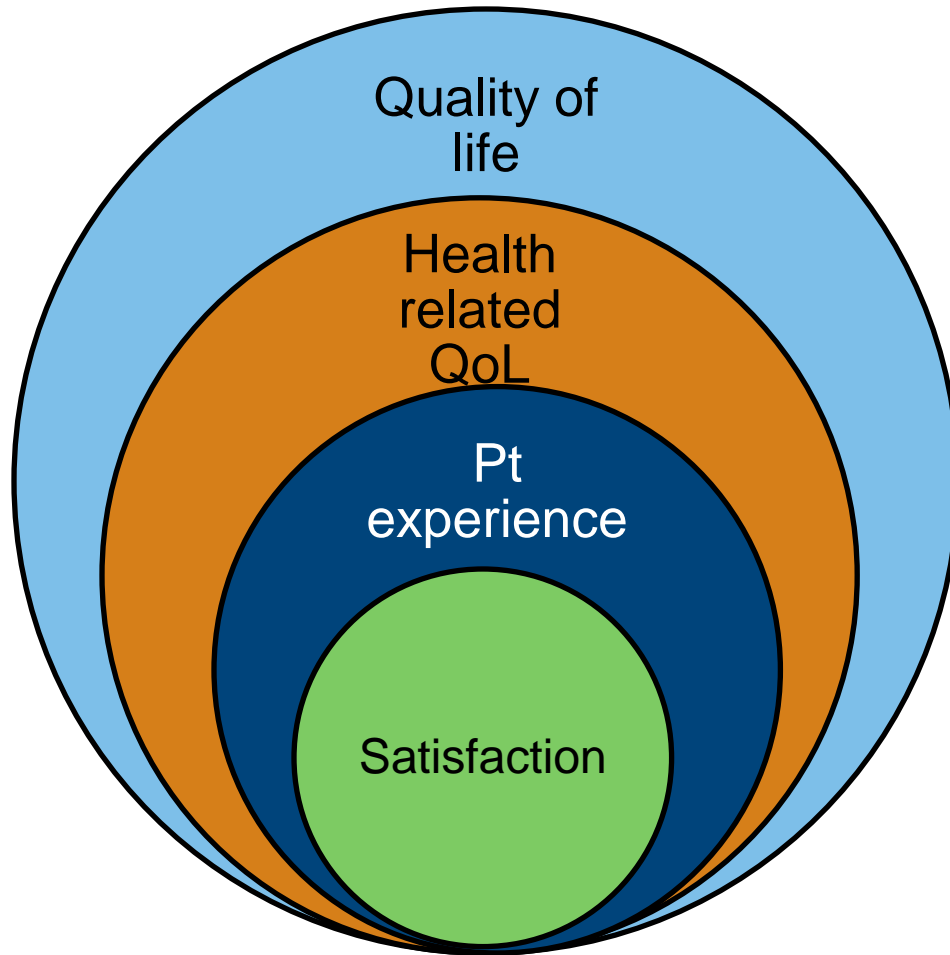
# Definitions



**Quality of life:** subjective evaluations of positive and negative aspects of life” (WHOQOL Group)

**Health-related quality of life:** “individual’s perceived physical and mental health” (CDC)

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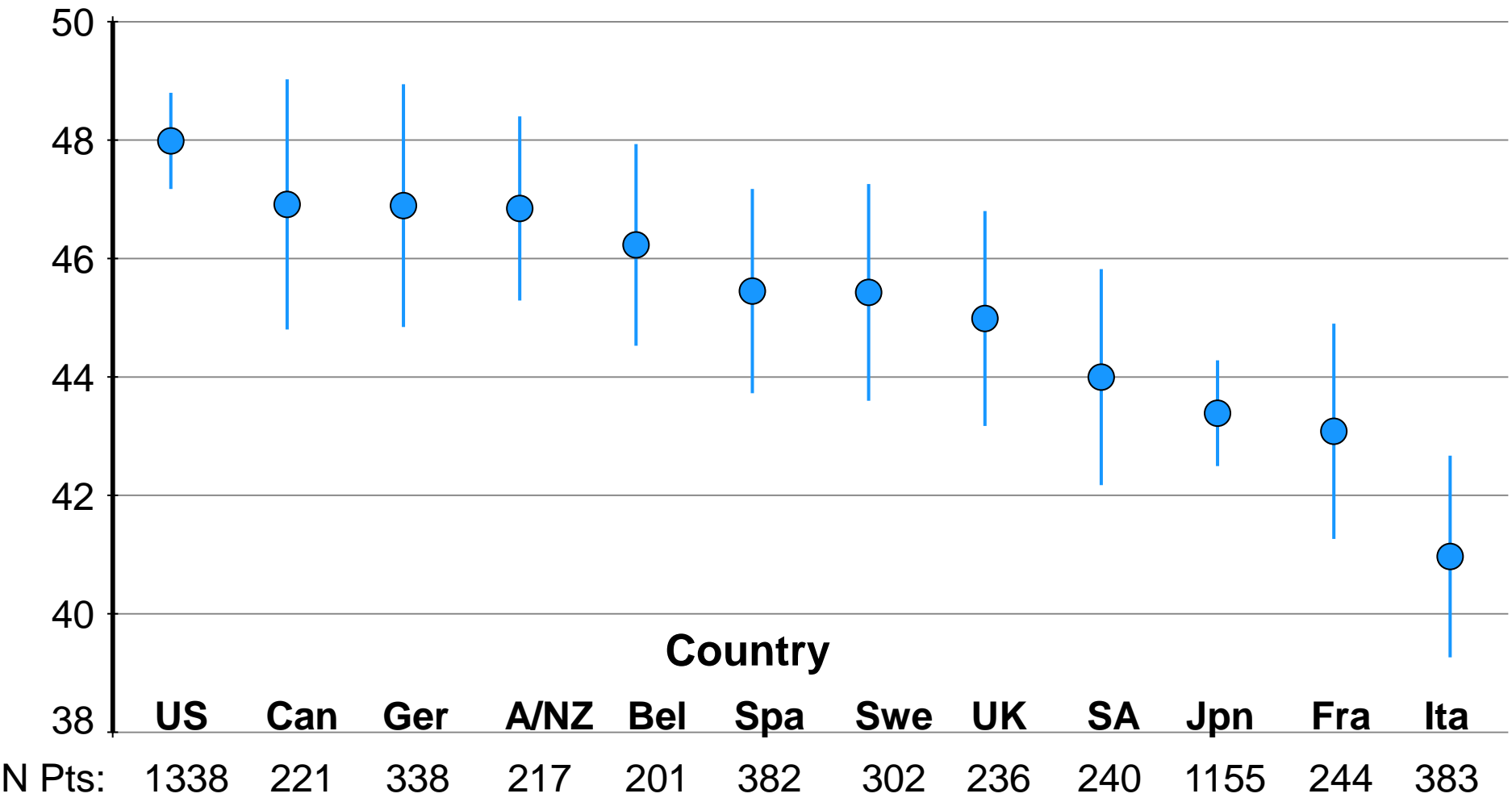
**Patient experience:** “the sum of all interactions that influence patient perceptions across the continuum of care” (The Beryl Institute)

**Patient satisfaction:** subjective measure of the extent to which the patient's expectations are met

# KDQoL Mental Component Summary Score

DOPPS 4 (2009-2011)

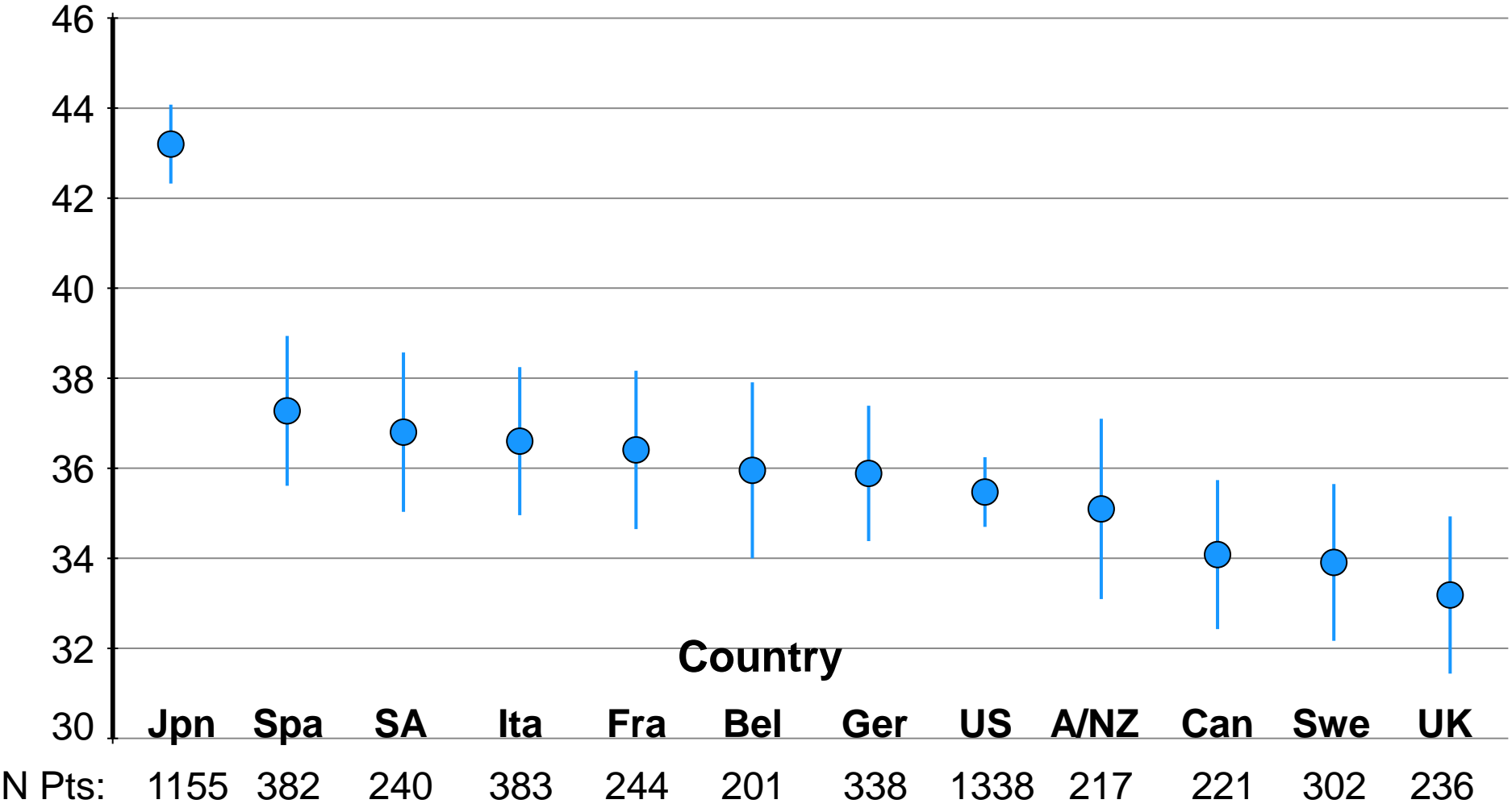
Age-adjusted mean MCS score (95% CI)



# KDQoL Physical component summary score

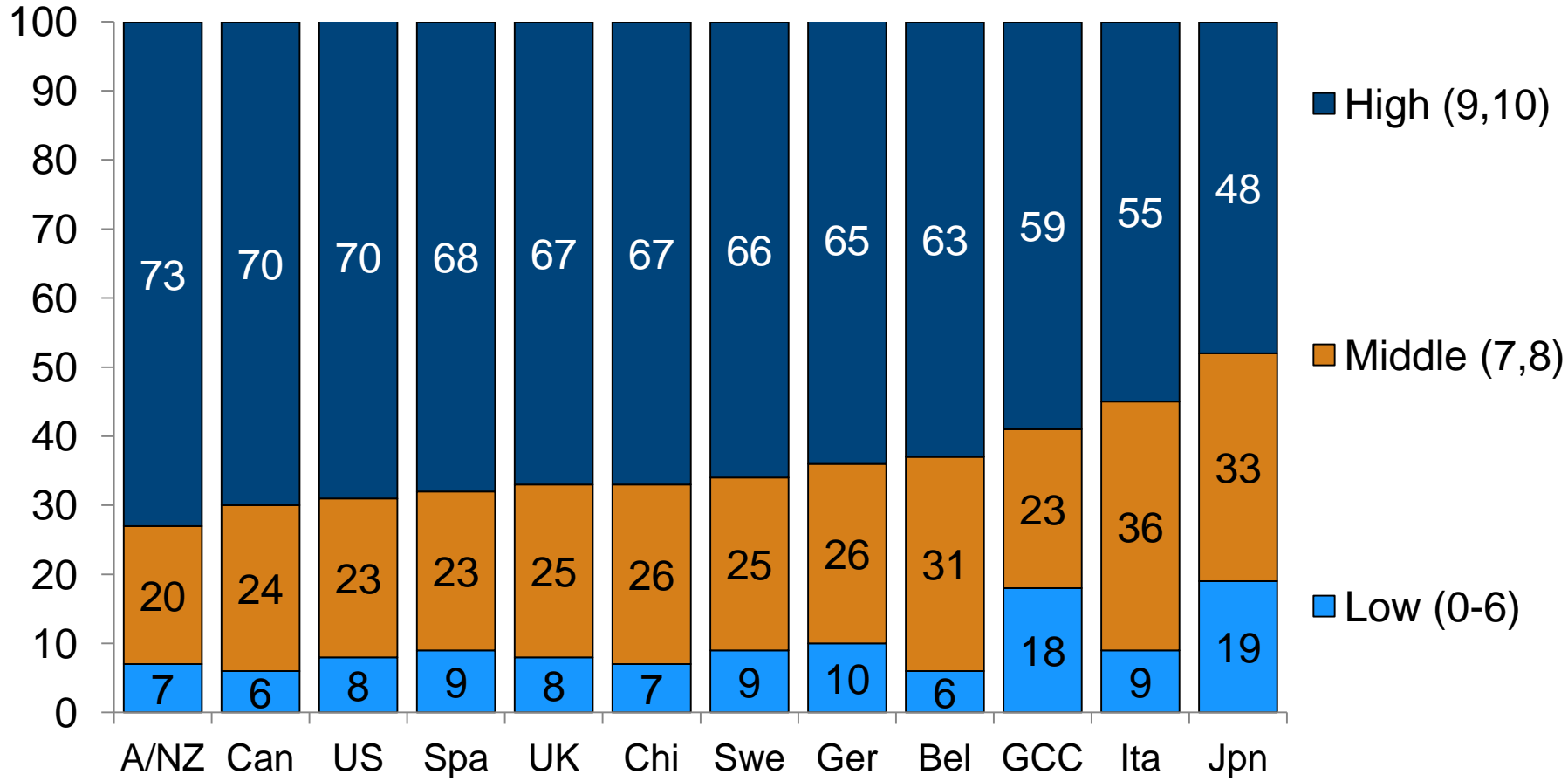
DOPPS 4 (2009-2011)

Age-adjusted mean PCS score (95% CI)



# How would you rate your dialysis center?

% of patients

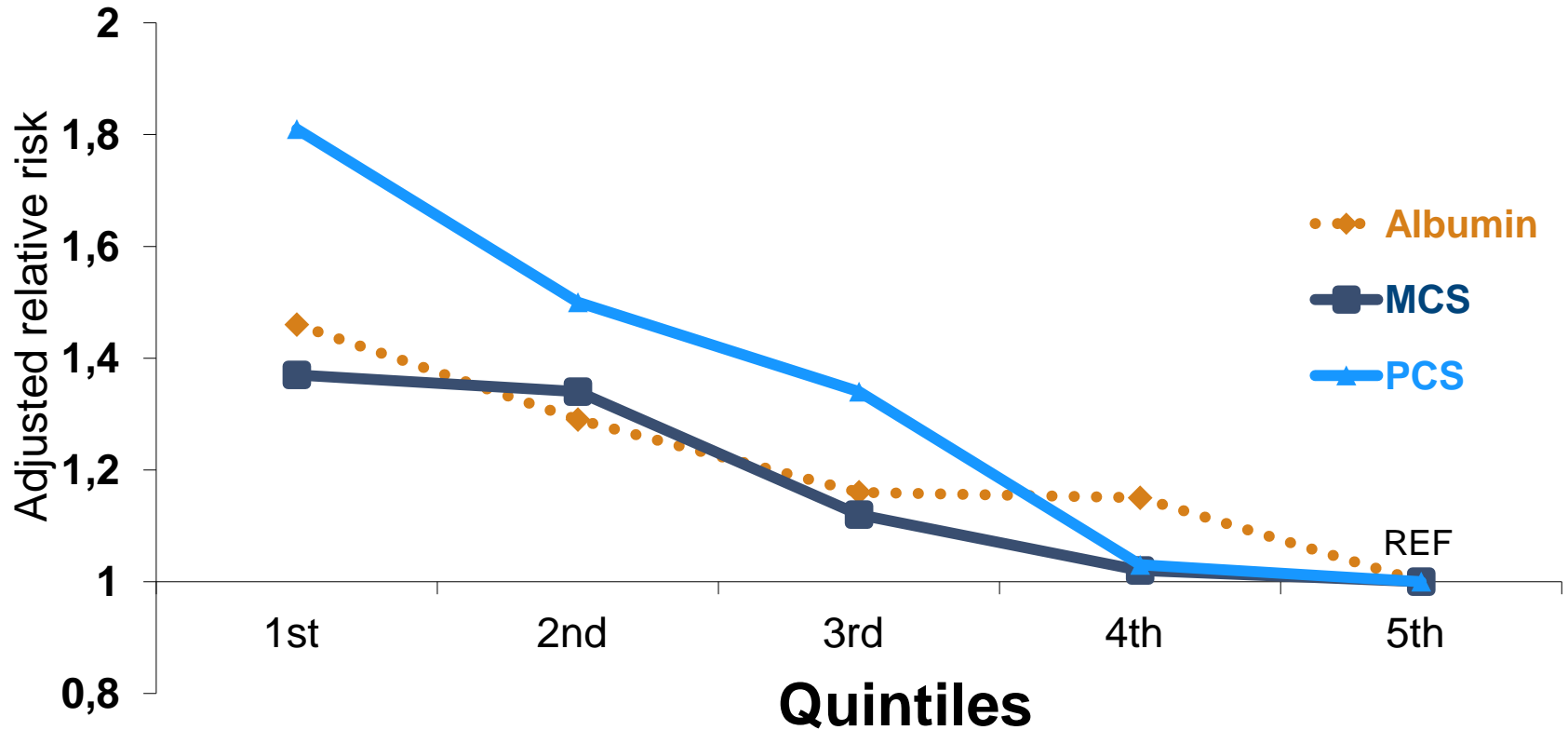


N Pts= 320 311 1102 467 317 997 316 452 245 447 395 1541

# **WHY IS THE PATIENT EXPERIENCE IMPORTANT?**

**-The patient past experience as a determinant of clinical practices**

# HRQoL as a Strong Predictor of Mortality



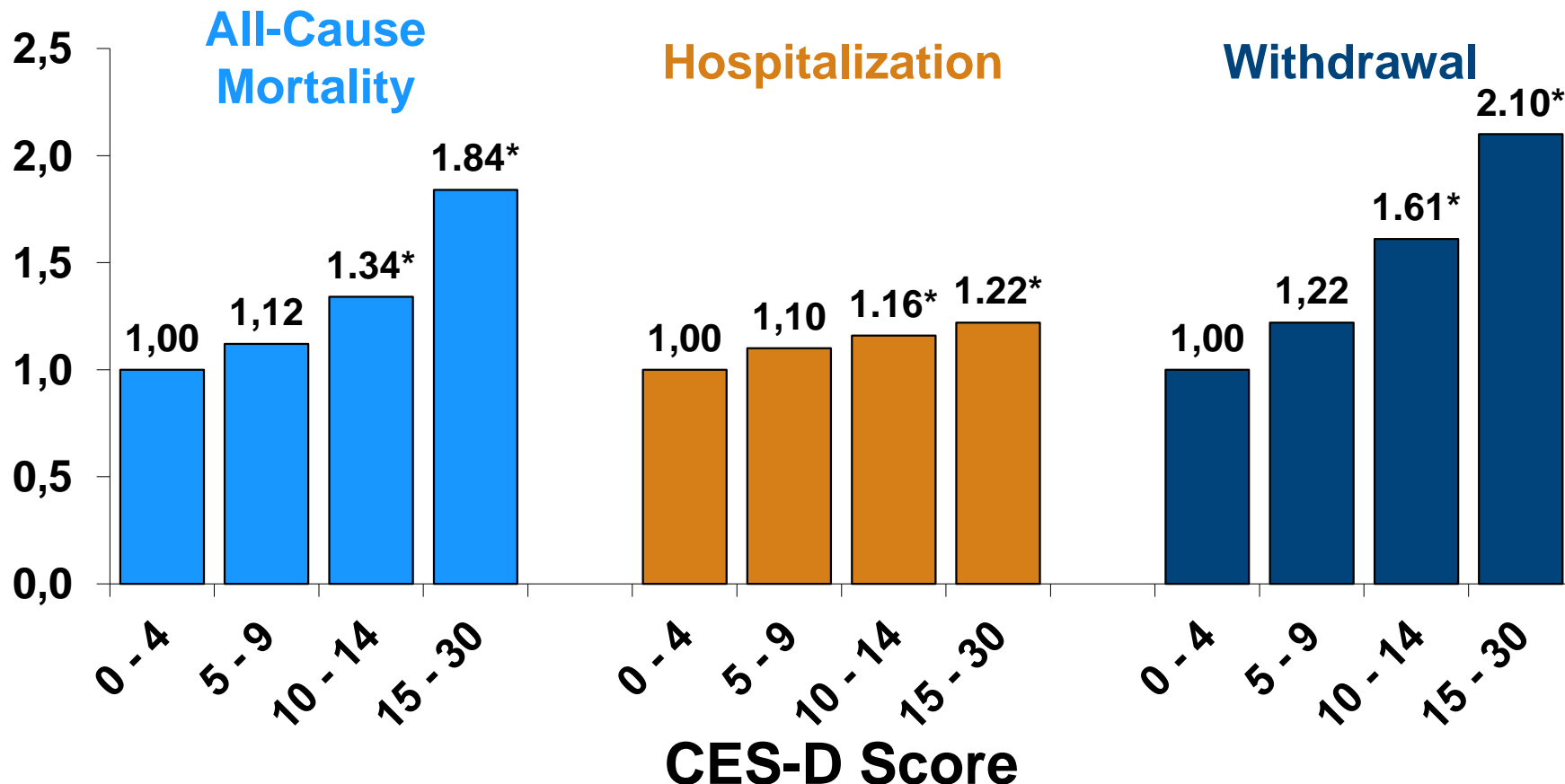
Each line shows a significant trend (each  $P < 0.001$ )

MCS = mental component summary; PCS = physical component summary



# Depressive Symptoms and Adverse Outcomes

Hazard Ratio<sup>†</sup>



<sup>†</sup> Model adjusted for age, sex, black race, living status, marital status, education level, employment status, 14 summary comorbid conditions, albumin, time on dialysis, country (N=9,382)

\* p<0.05 compared to reference (CES-D = 0-4)

# Limitations of Current Practices

- **Validated instruments are long and time-consuming**
  - Too burdensome to be done more than once/twice a year
- **May not assess factors that are most important to patients**
- **Selection bias: only completed by patients who are “healthier” and more willing to spend time doing so (or those who are very unhappy)**
- **Patients are reporting “questionnaire fatigue” and frustration for lack of feedback**

# D P P S

## DIALYSIS OUTCOMES AND PRACTICE PATTERNS STUDY

AJKD

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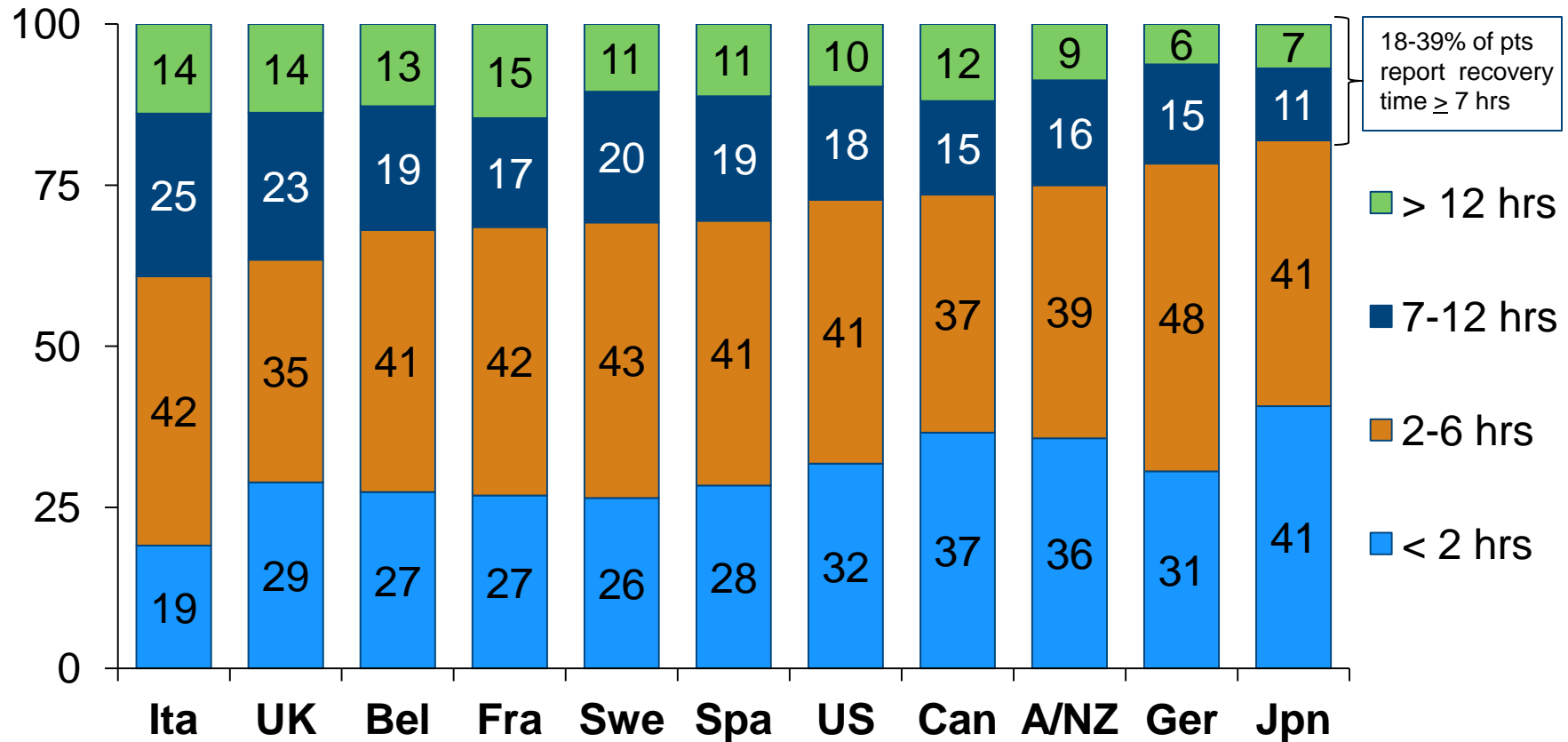
Original Investigation

### **Recovery Time, Quality of Life, and Mortality in Hemodialysis Patients: The Dialysis Outcomes and Practice Patterns Study (DOPPS)**

*Hugh C. Rayner, MD, FRCP,<sup>1</sup> Lindsay Zepel, MS,<sup>2</sup> Douglas S. Fuller, MS,<sup>2</sup>  
Hal Morgenstern, PhD,<sup>2,3,4</sup> Angelo Karaboyas, MS,<sup>2</sup> Bruce F. Culleton, MD,<sup>5</sup>  
Donna L. Mapes, PhD,<sup>2</sup> Antonio A. Lopes, MD, MPH, PhD,<sup>6</sup> Brenda W. Gillespie, PhD,<sup>7</sup>  
Takeshi Hasegawa, MD,<sup>8</sup> Rajiv Saran, MD,<sup>7</sup> Francesca Tentori, MD,<sup>2,9</sup>  
Manfred Hecking, MD,<sup>10</sup> Ronald L. Pisoni, PhD,<sup>2</sup> and Bruce M. Robinson, MD<sup>2,7</sup>*

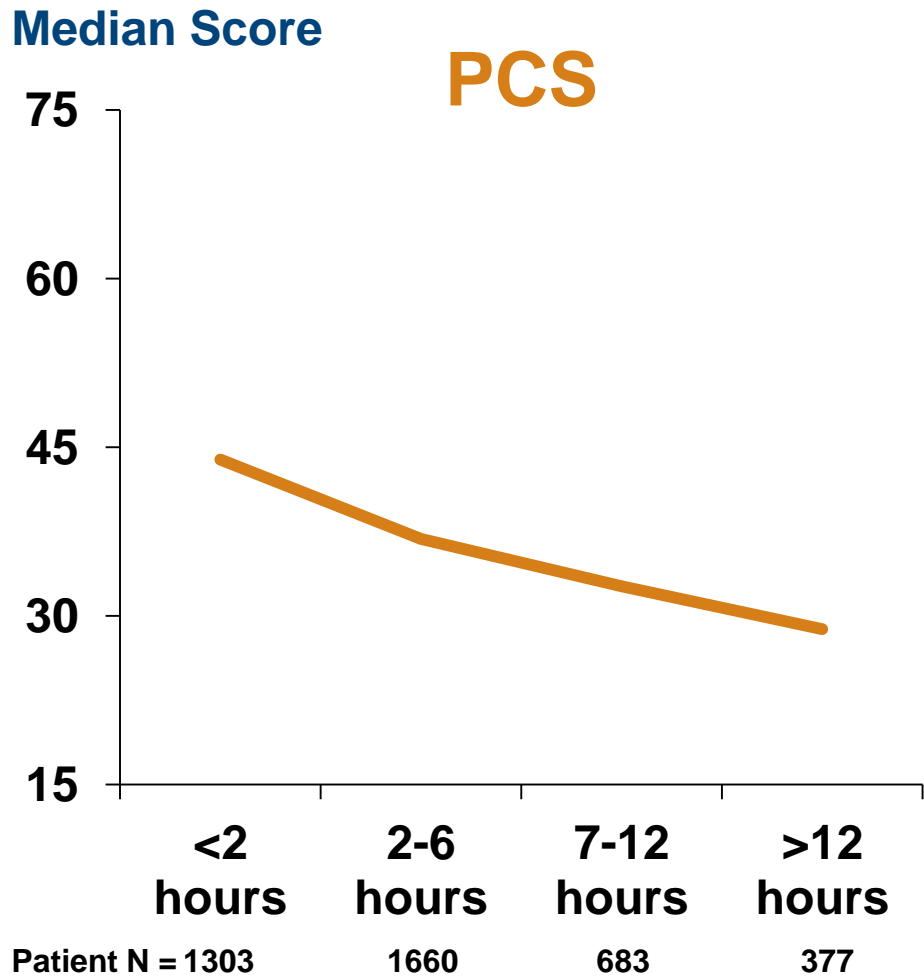
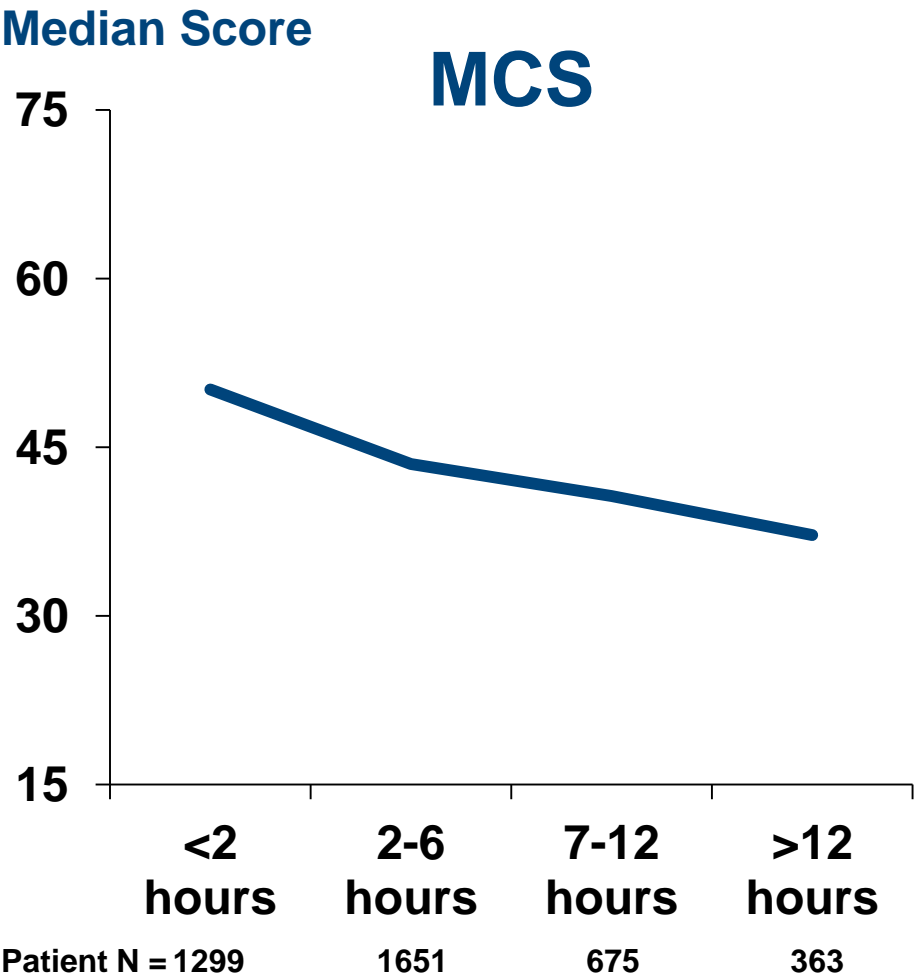
# Self-Reported Recovery Time

% of Patients



N Patients: 252 369 268 343 448 483 1513 419 276 298 1371

# Longer recovery time is correlated with lower HrQuality of life



**Patient-reported Recovery Time**

**Patient-reported Recovery Time**

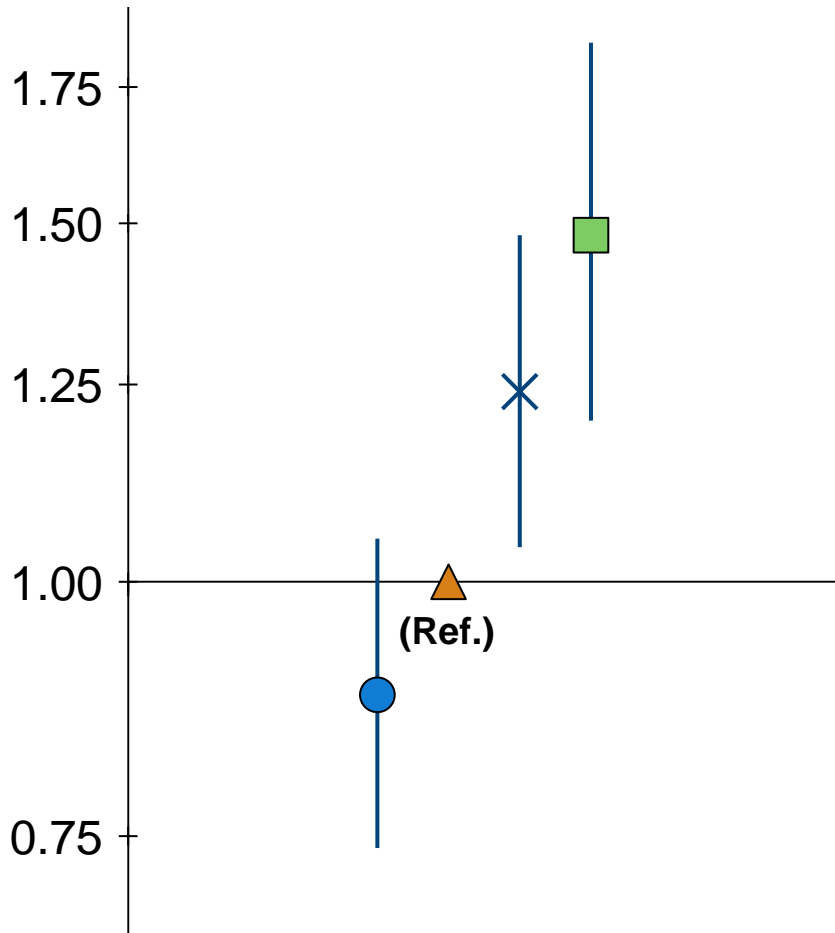
DOPPS 4 Patient Questionnaire

MCS=Mental Component Summary; PCS=Physical Component Summary

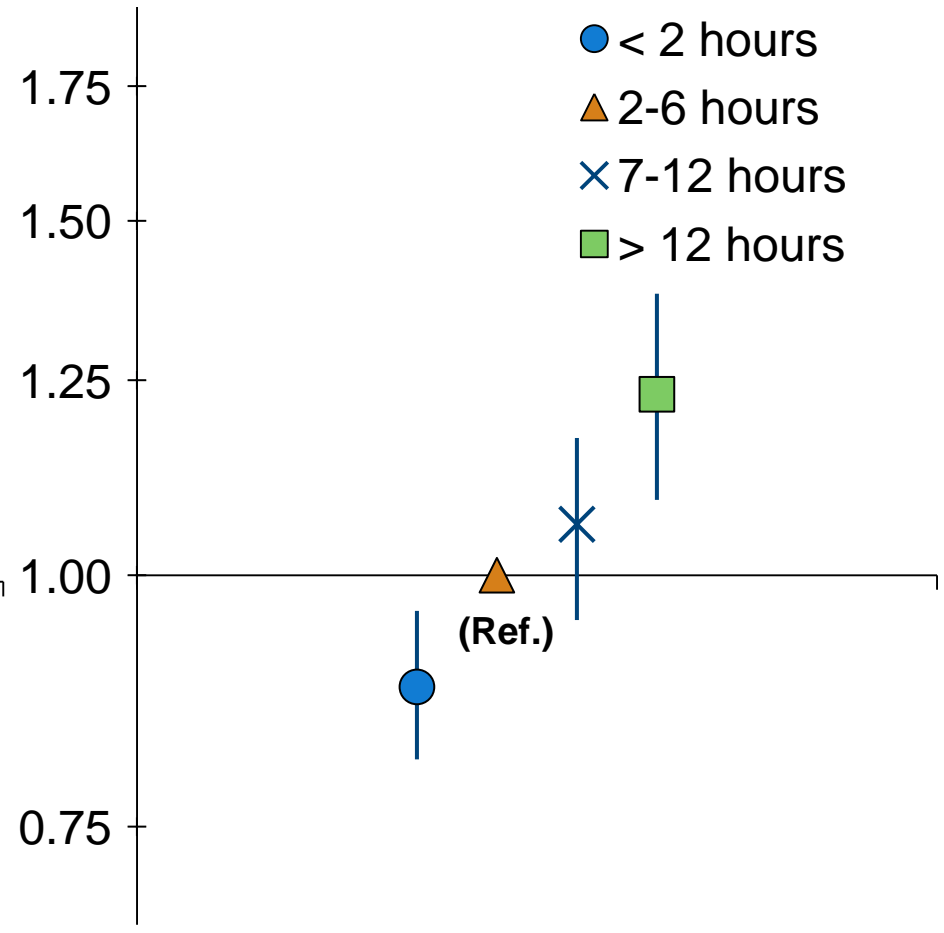


# Recovery Time and Mortality/Hospitalization

## HR (95% CI) for mortality



## HR (95% CI) for first hospitalization

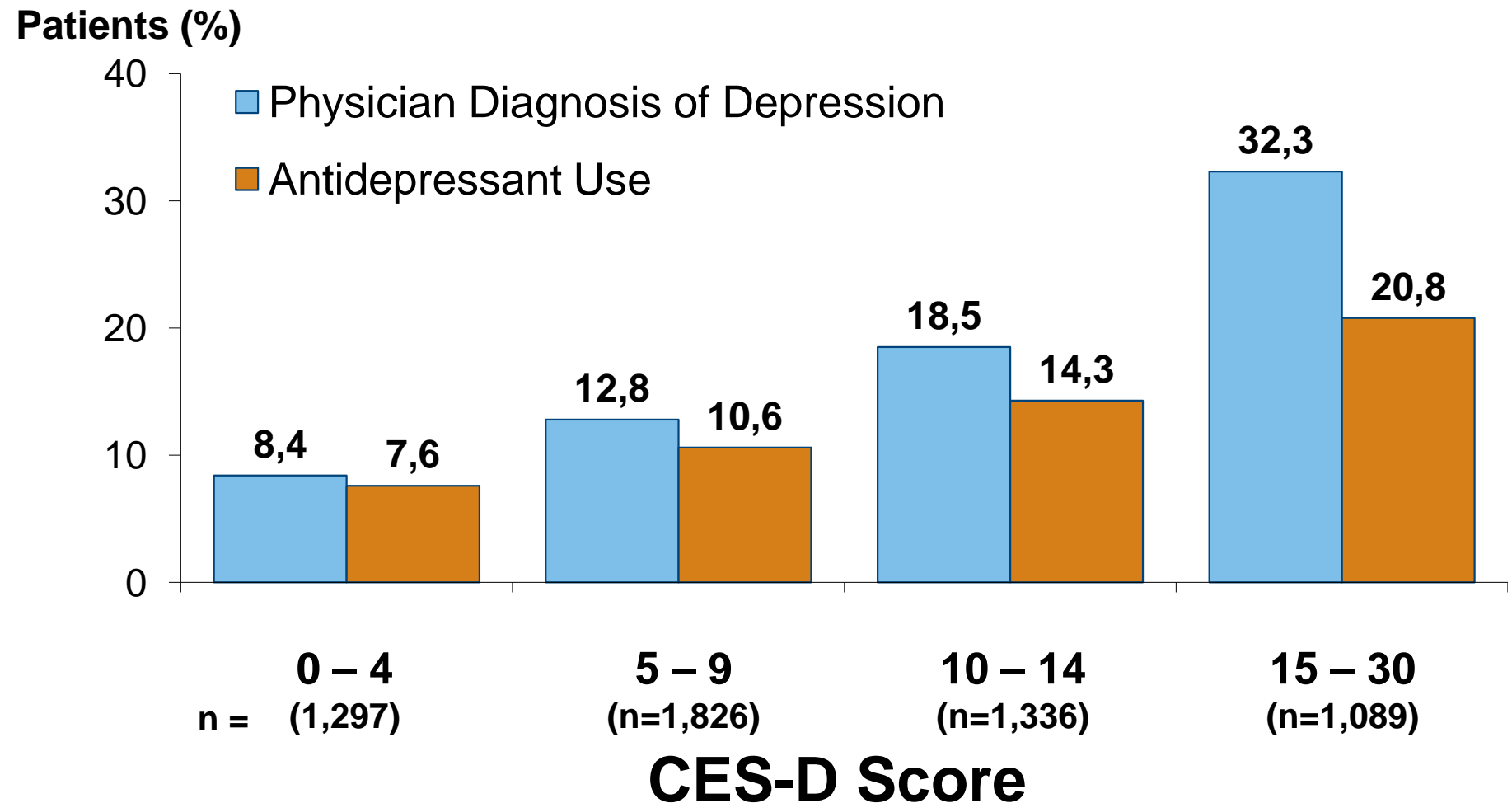


Cox models stratified by country and race (US black only) and use a robust "sandwich" variance estimator;  
Demographic adjustments: sex, age, time on dialysis, BMI, and 14 summary comorbidities;  
HR-QOL adjustments: RAPA, depression, sleep problems, pruritus, ADL count, employment, PCS, MCS

Rayner et al. *Am J Kidney Dis* 64(1):86-94, 2014

# **OPPORTUNITIES TO IMPROVE THE PATIENT EXPERIENCE**

# Treatment of Depression





# Summary

- **The good: Greater attention paid to the patient experience both by clinicians and policy makers**
- **The not so good: Routine assessment of quality of life and satisfaction are mandated, but available instruments have important limitations**
- **The bad (aka, opportunities for improvement):**
  - **Lack of evidence supporting specific interventions to improve the patient experience**
  - **Limited engagement of patients in key decisions regarding their treatment (e.g. transitions to/out of dialysis)**