CKD Patient-Reported Outcomes

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PROM/PREM

- Come directly from patients about how they function or feel in relation to a health condition and its therapy[1]
- Often greatest importance to patients
  - Knowledge
  - Symptoms
  - Behaviours (adherence, self-management)
  - Abilities (functional status)
  - General perceptions or feelings of well-being (quality of life)
  - Satisfaction with treatment
- Collected using an instrument
  - generic, disease-specific, condition-specific
- Increasing recognition/use in clinical nephrology research[2,3,4]
  - SONG (Standardised Outcomes in Nephrology)

1. Frank et al. JAMA, 2014;312:1513-1514
2. Cukor et al. CJASN, 2016;11:1703-1712.
3. Evangeledis et al. AJKN, DOI: org/10.1053/j.ajkd.2016.11.029
4. Tong et al CJASN, 2017;12:454-466

PROMS
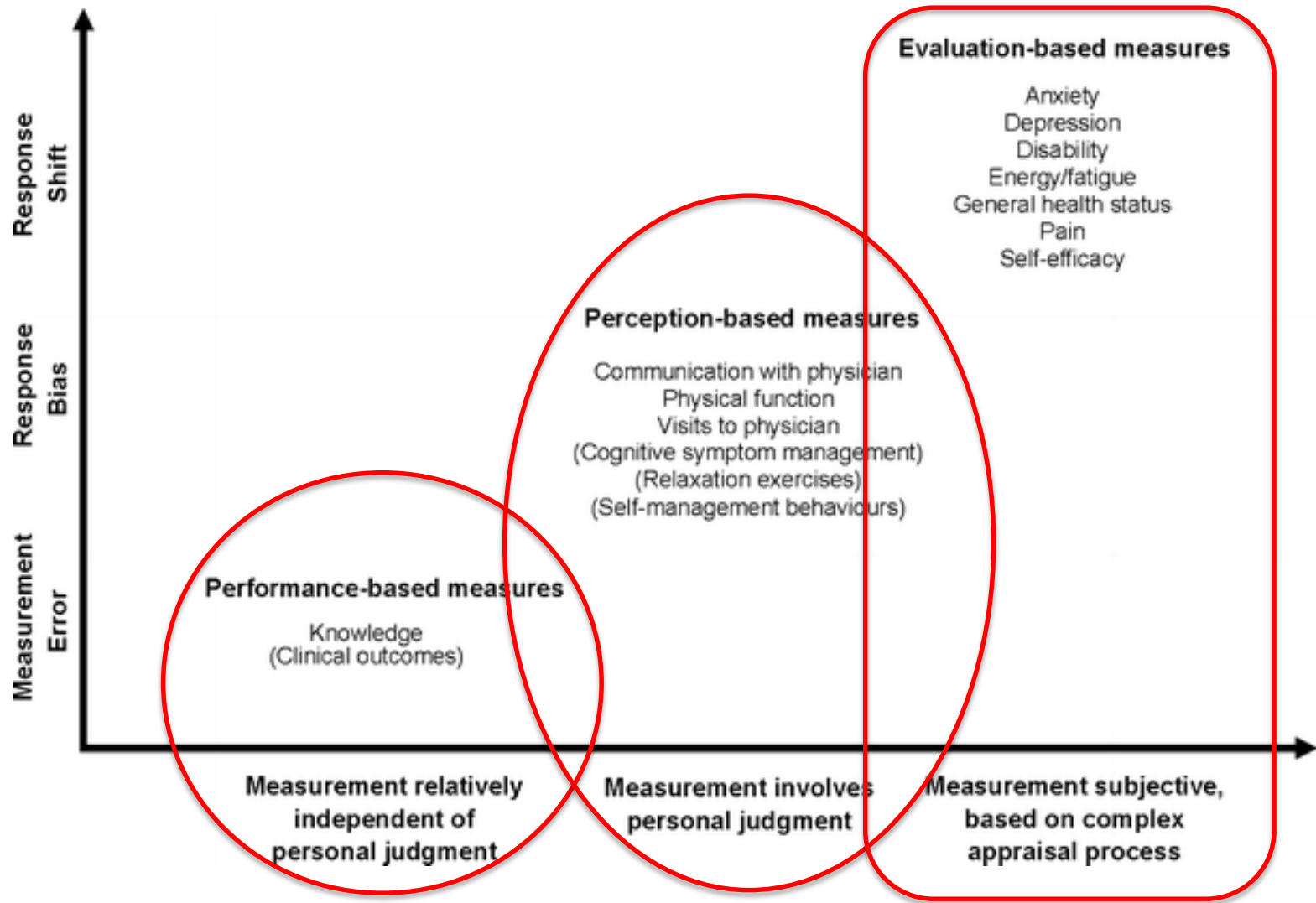
Nolte et al (2013) Quality of Life Research, 22(7), 1655-1664

CKD PROMs

- Performance-based
  - CKD knowledge^
- Perception-based
  - CKD self-management behaviours^
  - Physical activity^
  - Decision-making^
  - Telehealth#
  - Health literacy^
- Evaluation-based
  - CKD symptoms^#
  - Health-related quality of life^
  - Chronic disease self-efficacy
  - Patient satisfaction^#

^existing (tend to be recently developed)
#investigator developed

Studies

- Practice Improvement streams
  - Primary and community models of care
  - Frail, complex and elderly patient with CKD
- Designs
  - Randomised control trial
  - Pre/post intervention (Kathryn Havas)
  - Cohort
  - Cross-sectional
  - Translation/validation (Arabic, Vietnamese)
 - Mixed methods

CKD Symptoms

- CKD studies limited
  - Small number of symptoms and their prevalence
  - Mostly haemodialysis population (↑ in kidney supportive care)
- Symptoms have multidimensional features
  1) Occurrence
  2) Severity
  3) Distress
  4) Frequency
- When a clinician focuses only on highly prevalent symptoms, other significant (frequent, distressing or severe) symptoms remain under-recognised and unrelieved
- Assessment of all symptom dimensions helps to estimate the total symptom burden

|	Palliative care Outcome Scale-Symptoms – Renal (iPOS-R)
No. of symptoms	17 + 3 free fields
Ideal population	CKD stage 5 (KSC) - only
Occurrence	✔
Distress	✔ (0-4)
Severity	✗
Frequency	✗
Benefits	▪ Simple ▪ Quick ▪ Easy to use ▪ Clinical application
Limitations	▪ Tested only in KSC ▪ Limited dimension

CKD Symptom Clusters

Almutary H, Douglas C & Bonner A. 2016. Multidimensional symptom clusters: An exploratory factor analysis in advanced chronic kidney disease. *J Adv Nurs*, 72(10):2389-2400.
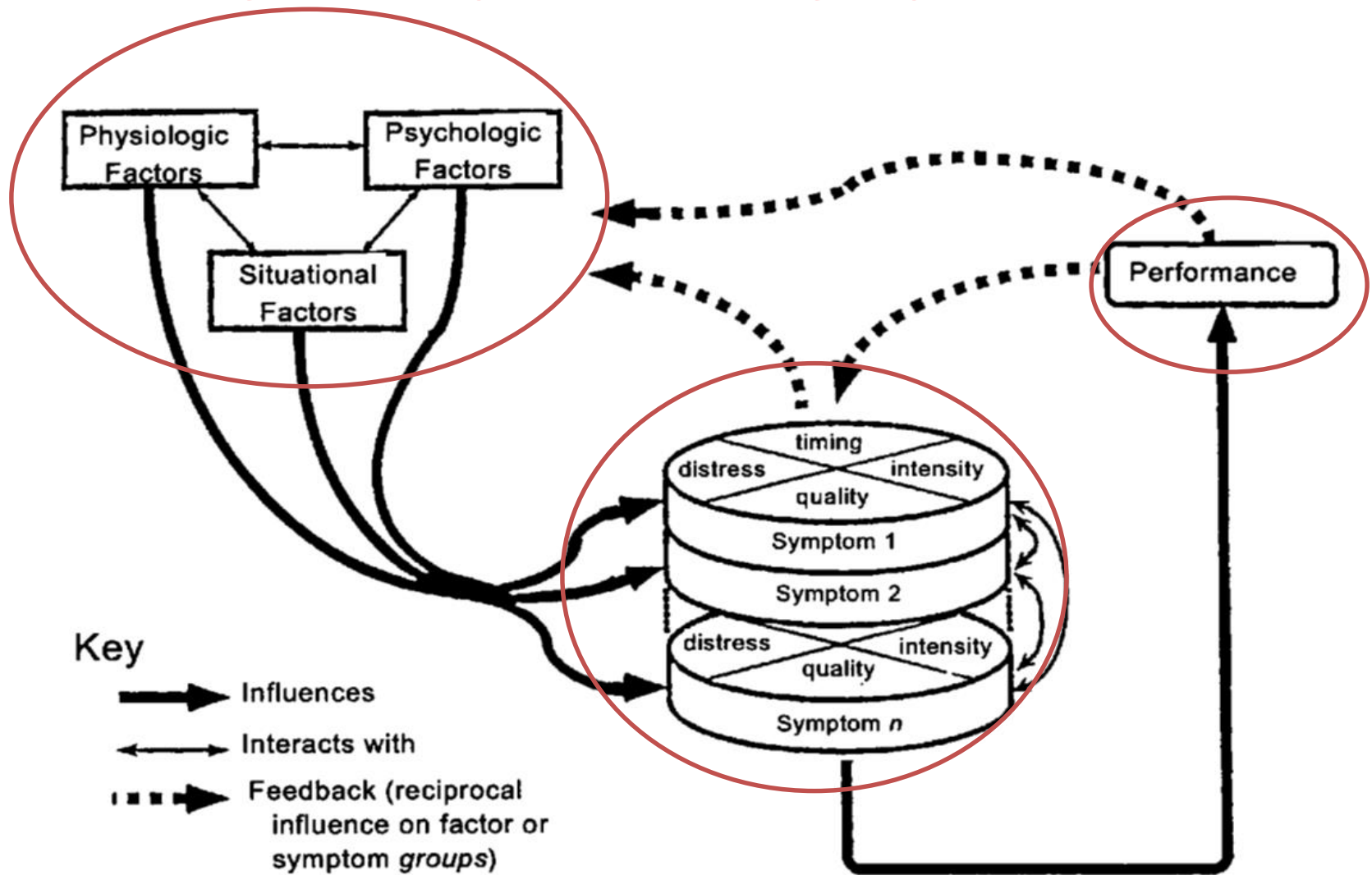

A. Fatigue — with clusters 1, 2, 3, 4, 5

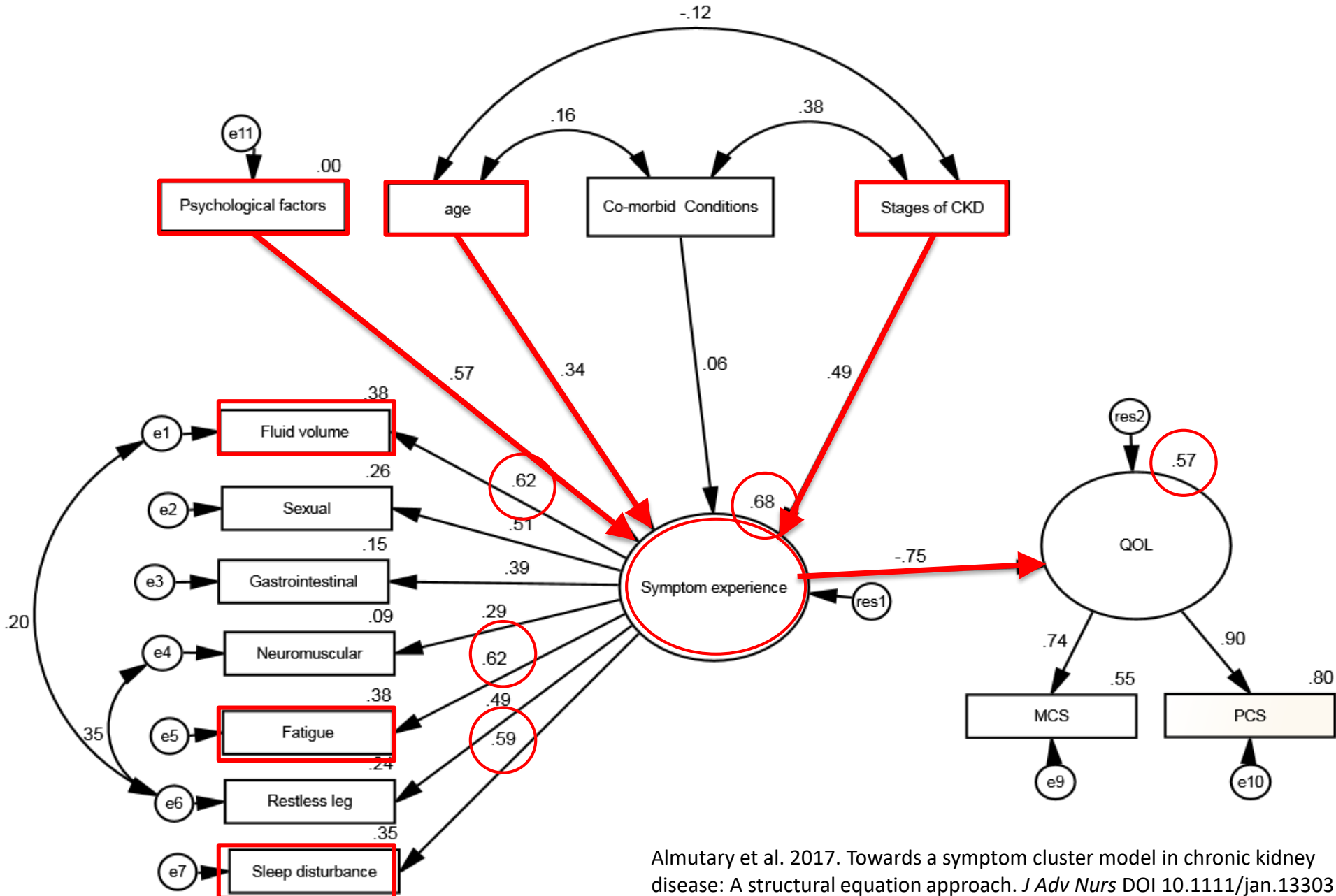B. Restless legs / Sleep disturbance — with clusters 1, 2, 5
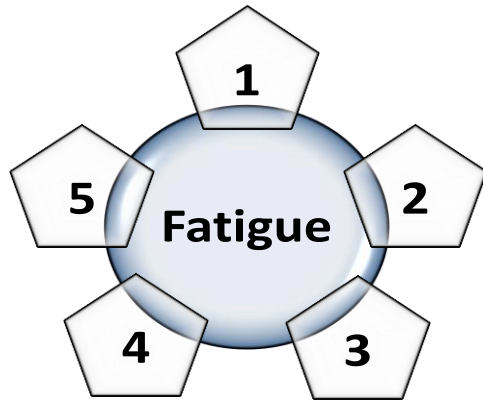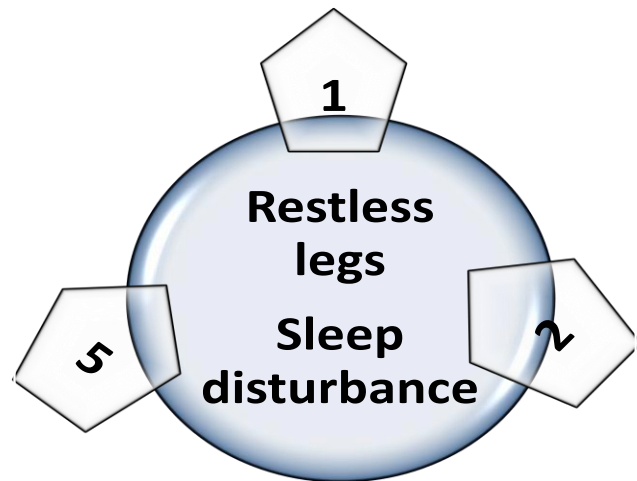
1. Fluid volume symptom cluster

2. Neuromuscular symptom cluster

3. Gastrointestinal symptom cluster

4. Sexual symptom cluster

5. Psychological symptom cluster

Theory of Unpleasant Symptoms (TUS)

(Lenz & Pugh, 2014)

CKD Symptom Model

Almutary et al. 2017. Towards a symptom cluster model in chronic kidney disease: A structural equation approach. *J Adv Nurs* DOI 10.1111/jan.13303

Dissemination

- Publications (see also QUT ePrints https://eprints.qut.edu.au/)
  - Journal articles + manuscripts under review
  - Theses
- Conferences
  - National
  - International
- Many studies in progress

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