

ASN DIALYSIS ADVISORY GROUP

ASN DIALYSIS CURRICULUM

Quality of Life in Dialysis

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DISCLOSURES:

- None

Outline of Talk

⇒ **What is Quality of Life (Definition)?**

⇒ What is QOL on dialysis?

⇒ **What contributes to this?**

⇒ **What basic literature is important?**

⇒ **How do we practically assess QOL?**

⇒ **How do we improve it?**

Case to illustrate the issues...

Mr M is a 73 yo caucasian gentleman, on chronic HD x 4 years due to T2 DM

- **He feels constant fatigue, frequent back pain, and intermittent pruritus**
- **He has compression fractures, and insists on stopping treatments when in too much pain**
- **He wants to know 3 things:**
 - 'Doc, am I like everyone else?'
 - 'What can you do to help me feel better?'
 - 'Is this as good as it gets?'




What is QOL?

Active learning exercise:

- How would you define quality of life for Dialysis patients for whom you have cared?

Some other definitions:

- QOL – A complete state of physical, mental, and social well being and not merely an absence of disease or infirmity.*
 - Health related QOL – The health demands that are intimately related to health or disease.**
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What contributes to QOL?

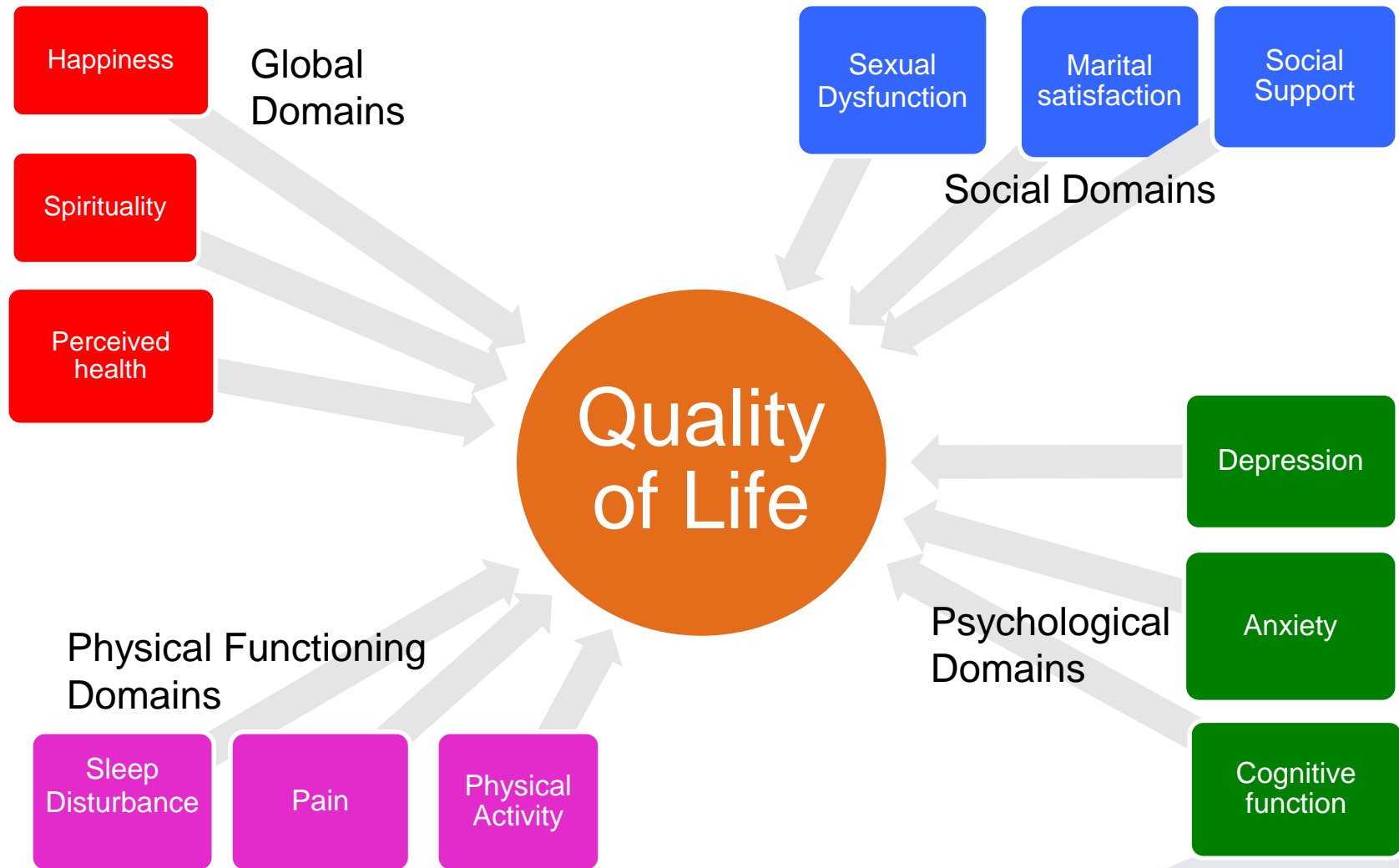
**Doctors may focus on:
Control of:**

- Acid-base status
- BP and volume status
- Cardiovascular Risk
- Diet/nutrition
- Mineral/Bone disorders
- Small/middle molecules

**Patients may focus on:
How do I feel !?!**



What impacts a patient's QOL?



How do we assess general QOL?

Questionnaire	Population	Domains
Kidney Disease QOL Questionnaire	HD	QOL & Symptoms
CHOICE Questionnaire	HD and PD	QOL
McGill Quality of Life Scale	Kidney disease	QOL
Illness Effects Questionnaire	HD	QOL & effects
Dialysis Symptom Index	HD	P & E Symptoms*
Modified Edmonton Symptom Scale	HD	P & E Symptoms
Patient Symptom Form	CKD	P & E Symptoms

Tool Comparison for Specific Selected Symptoms Affecting QOL

Domain	Validated Tools: Examples	Interventions include:	Comments
Social Support	KDQOL-SF SF-36 MSP	Social Support Group	' SS → improved compliance & access to care
Anxiety	SCID-1 PRIME-MD	CBT Pharmacologic Rx	Check for Depression
Pain	Bodily Pain Scale MPG	Pain Management WHO analgesic ladder Exercise	Adjust meds for kidney and liver disease
Sexual Dysfunction	IIEF-5	PDE-5 Inhibitors	Minimal data for Rx in ESRD



Typical Symptomatology (1)

↑ symptoms with ↑age & comorbidity

• Fatigue most prevalent:

• 82% (HD) – 87% (PD)

• Itching, muscle cramps, SOB: each >40%

Dialysis dose not associated with sx burden

Physical symptoms only ONE PART of 'Quality of Life'





Typical Symptomatology (2)


Most prevalent symptoms

- Dry skin (72%), fatigue (69%), itching (54%), bone & joint pain (50%)

Most bothersome symptoms

- Bone & joint pain, sexual arousal
- Half of symptoms were reported as 'more than somewhat bothersome'

Treatment - examples

- Dry Skin & Pruritus: Emollients, dermatology referral, dietary counseling
 - Fatigue: Can assess and treat for OSA (obstructive sleep apnea)
 - Bone & Joint Pain: WHO analgesic ladder, CKD-MBD treatment
- 



Physical Functioning Domains

Pain

Etiologies:

- **Treatment related – needles, fluid & electrolyte shifts**
- **Renal bone disease**
- **Comorbidity related**

Common (25-50%) & severe

Associated with:

- **depression, low QOL scores, insomnia, anxiety, dialysis withdrawal**



Physical Functioning Domains

Sleep Disturbances

Etiologies include:

- **Sleep apnea, Restless leg syndrome (RLS), altered sleep-wake cycles**

Common (41-83%) & associated with:

- **Pain, depression, poor Global QOL, adverse cardiovascular outcomes**

Consider sleep hygiene assessment before pharmacologic Rx

Polysomnagraphy +/- CPAP, RLS therapy

- **Including d/c antidopaminergic agents**
- 

Social Domains: Sexual Dysfunction

Etiologies include:

- **Vascular disease, hormonal changes, medications, psychological concerns**

Range of reported sx's from 33-83%

- **including ED, decreased interest, poor arousal**
- **One of the most bothersome symptoms**

Treatment –

- **18% of those w/sx's received therapy**
- **medications effective vs placebo**
- **Phosphodiesterase inhibitors have been used:**
 - **caution for use in population with high burden of cardiovascular disease**



Social Domains: Social Support

Types: support via:

- Cognitive – information/knowledge
- Emotional – concerns & feelings
- Materials – goods & services

Improvements in:

- aid and access to care
- symptoms of depression and anxiety
- adherence, direct physiologic effects.

Demonstrated relationships between social supports and:

- Items listed above, also
- quality of life and survival



Psychological Domains

Depression

Most common psychiatric disorder in chronic dialysis patients

- **Prevalence estimates ~20% of MDD**
- **Dx via DSM-IV criteria**
- **Screening tools include BDI, PHQ-9, CES-D**

Therapies: non- and pharmacological

- **SSRIs with few side effects, low dose & titrate**
- **Counseling (eg CBT), exercise, Rx anxiety**
- **Understudied**



Psychological Domains

Cognitive Impairment (1)

Definition of cognitive impairment:

- **new deficit e 2 areas of cognitive functioning**
 - Memory, executive function, attention/processing, perceptual motor, language
 - Diagnosis: 3MS score < 80 or MMSE < 24

- **Prevalence not well documented**
 - Chart dx - 2.9% but with formal testing:
 - 37% severe impairment
 - 36% moderate
 - 14% mild



Psychological Domains

Cognitive Impairment (2)

Etiologies (risk factors) include:

- **Traditional vascular: large & small vessel vascular disease (HTN, DM, age, smoking)**
- **Nontraditional vascular (hypercoagulable, hemostatic, inflammatory, oxidative stress)**
- **Nonvascular (Anemia, hyperparathyroidism, polypharmacy, sleep, age, education)**

Treatment should focus on above etiologies

Associated with:

- **increase risk of death, decreased quality of life, increased hospitalization/healthcare utilization**

Global Domains

Important to address general issues related to:

- **Spirituality**
- **Perception of health**
- **Overall happiness**

Our Patient...

Physical Function domains

- Sleep disturbance & pain addressed

Social domains

- Family and friends spent more time with him

Psychological domains

- Patient was depressed, started therapy

Global domains

- Patient assured that he was not 'alone' (major fear of his), ensured presence of spiritual support, daily activities



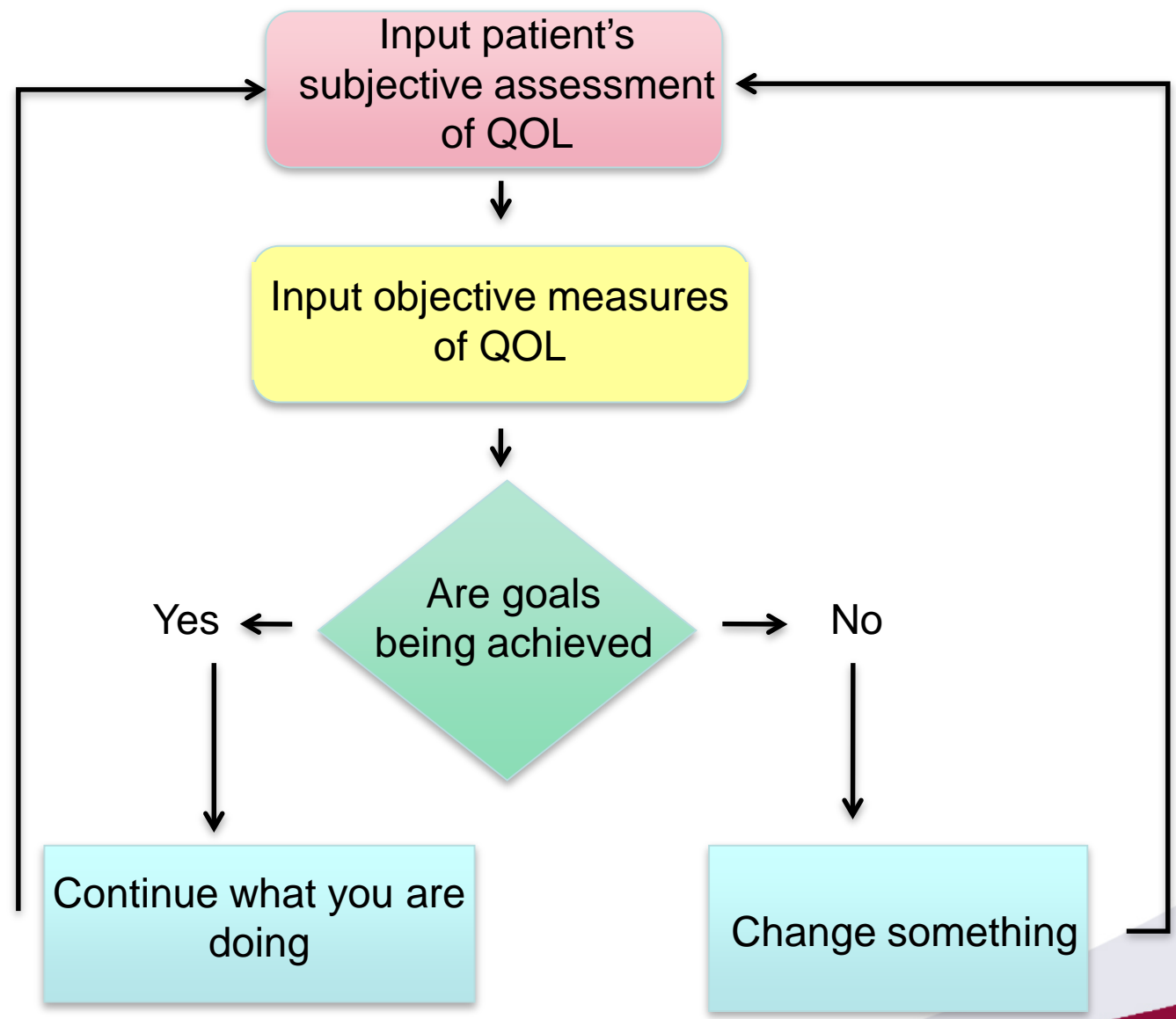
Easy Recipe: Quality of Life Assessment

SI

OI

AI

PI



Future Needs Assessment: Shaping the Research and Policy Agenda

Identification of broad themes to improve patient-centered outcomes

- Decrease morbidity and mortality
- Enhance Quality of Life
- From Kidney Research National Dialogue





“Several said the government is making a crucial mistake by rating performance [of dialysis clinics] by lab tests, not outcomes or measures that reflect patients’ quality of life. ‘Mortality, morbidity, and infection—that’s the bottom line,’ said [a former dialysis-clinic owner]. ‘It’s easy to adjust the labs. What good is it if you have good numbers, but everyone’s dying or in the hospital?’”

- Robin Fields, in “God Help You. You’re on Dialysis.” The Atlantic, December 2010

Quality of Life is...

What is important to the patient

- **Thus an essential component of what we should consider when we care for those around us**

Composed of Global, Psychological, Social, and Physical functioning domains

Assessable in the dialysis unit

Impacted by looking, listening and feeling with your patients