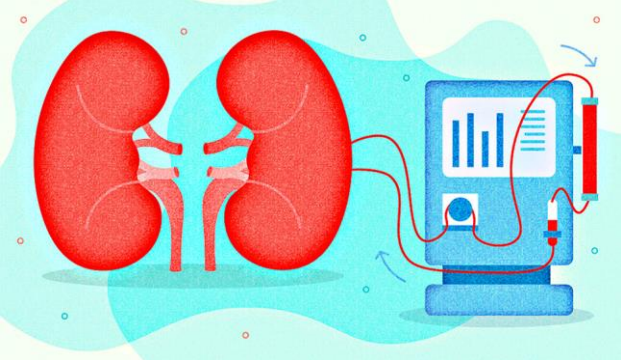
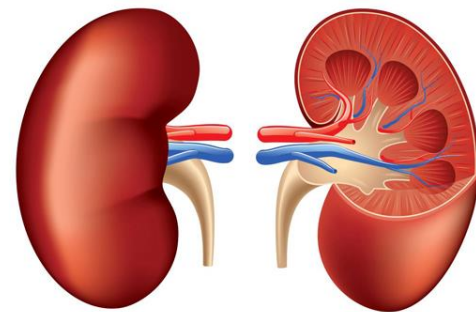




Educational Session



Health-related quality of life in people with chronic kidney disease

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Graduate Nurses' Foundation Sri Lanka

Outline

- Chronic kidney disease (CKD)
- Treatment options
- CKD in Sri Lanka
- Health-related quality of life (HRQoL)
- Factors affecting HRQoL
- Impact of CKD on HRQoL
- Recommendations

Chronic kidney disease

- Growing public health problem worldwide^{1,2}
- Prevalence – 10-15% of adult population¹
- Defined as decreased kidney function shown by GFR of less than 60 mL/min per 1.73 m² of at least 3 months duration²
- Disproportionate disease burden in low-middle or low-income countries³

¹Mandayam & Winkelmayer (2017) ; ²Webster, et al. (2017); ³Abraham, et al. (2016)

Chronic kidney disease

Grade	eGFR (mL/min/ 1.73m ²)	Description	Clinical features
1	≥ 90	Normal or increased eGFR	Asymptomatic
2	60-89	Slightly decreased eGFR	
3a	45-59	Mild – moderately decreased eGFR	
3b	30-44	Moderate – severely decreased eGFR	Symptomatic
4	15-29	Severely decreased eGFR	
5	< 15	Kidney failure – Non-dialysis	
5D		Dialysis dependent CKD 5 (or KF)	
5T		Kidney transplantation	

(Jager & Fraser, 2017; National Kidney Foundation, 2012; Webster, et al., 2017)

What are the common causes of CKD?

A

Age

B

Alcohol

C

Diabetes

D

High blood
pressure

Common CKD causes

- Hypertension
- Diabetes
- Glomerularnephritis
- Polycystic kidney disease
- Repeated UTI
- Nephrotoxic drugs
- CKDu

Chronic kidney disease

- Burdensome and affects people's lives in various ways
 - Compromised erythropoietin production- anaemia
 - Impaired vitamin D metabolism- mineral bone disease
 - Disruption of fluid and electrolyte homeostasis- hypertension and cardiovascular dysfunction
 - Build-up of waste products- impaired cognitive, gastrointestinal, and sexual function

Common CKD clinical manifestations

- Fatigue & lethargy
- Nausea & vomiting
- Anorexia
- Pain
- Pruritus, dry skin
- Shortness of breath
- Muscle cramps
- Sleep disturbances
- Anxiety & depression

Treatment options

- When reach kidney failure, kidney function is no longer able to sustain life over the long term.²
- Options for patients with kidney failure are
 - kidney replacement therapy (in the form of dialysis or kidney transplantation),
 - conservative care (also called palliation or non-dialytic care).



¹Mandayam & Winkelmayer (2017) ; ²Webster, et al. (2017); ³Abraham, et al. (2016)

CKD prevalence -Indian subcontinent

Country & Region	Number of Participants	Prevalence	Reference
Bangladesh			
Mirpur, Dhaka	1000	13.1%	(Huda, Alam, & Harun Ur, 2012)
Dhaka	1240	19.5%	(Hasan et al., 2012)
Dhaka	357	26.0%	(Anand et al., 2014)
India			
Chennai and Delhi	9797	8.7%	(Anand et al., 2015)
Multiple regions in India	5588	17.2%	(Singh et al., 2013)
North Gujarat and Saurashtra	2350	18.6%	(Trivedi et al., 2016)
Nepal			
Dharan	3200	10.6%	(Sharma et al., 2013)
Pakistan			
Karachi	2873	12.5%	(Jessani, Bux, & Jafar, 2014)
Karachi	350	16.6%	(Alam et al., 2014)
Sri Lanka			
Anuradhapura	6698	15.1%	(Jayatilake et al., 2013)

CKD Magnitude - Sri Lanka

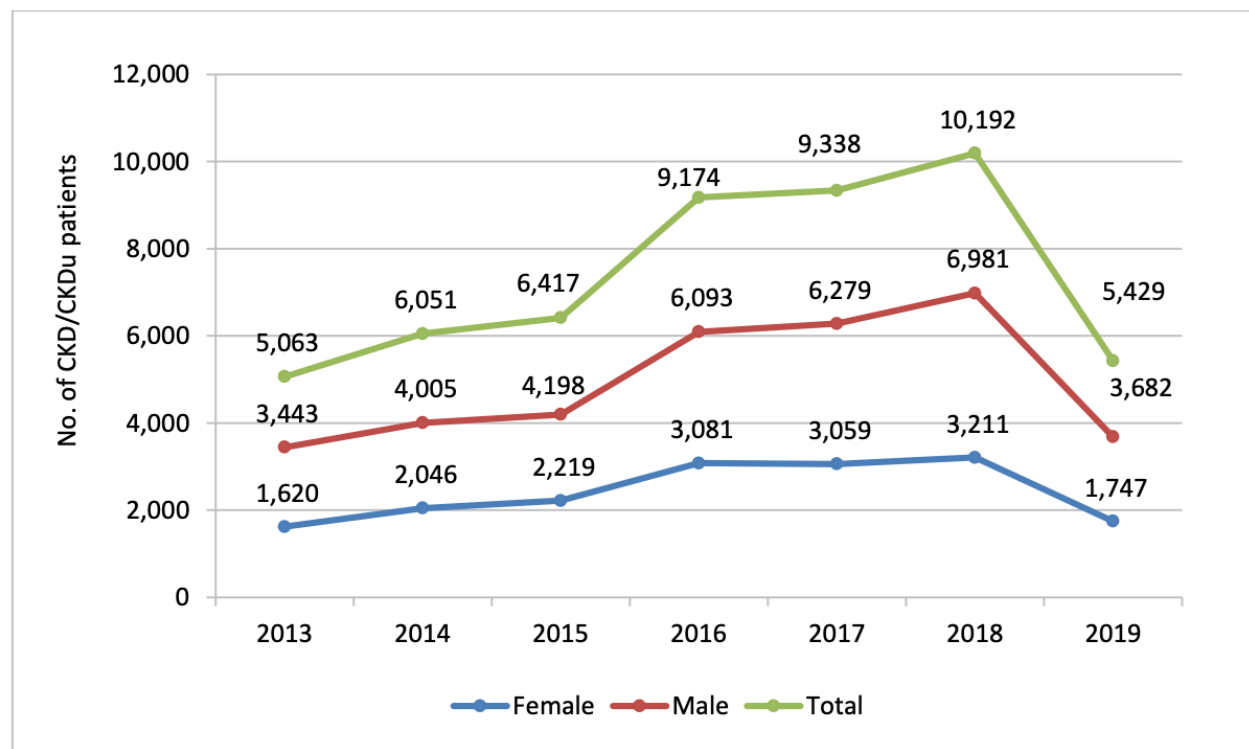


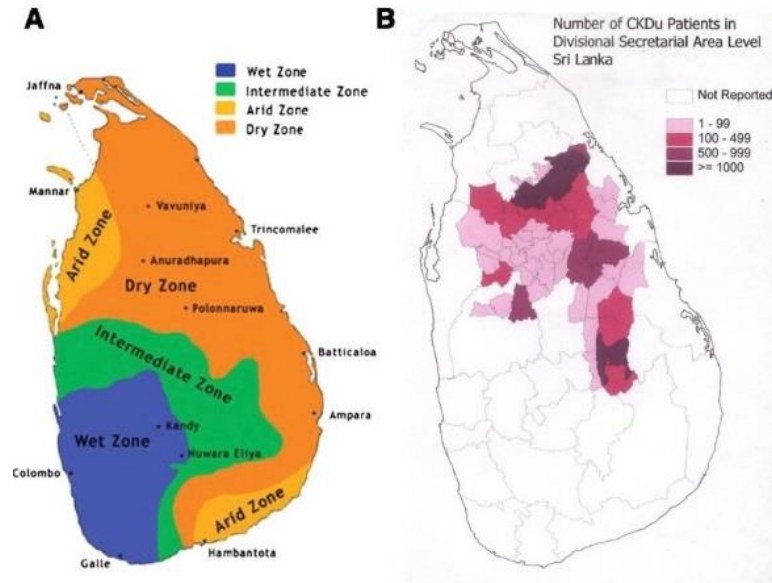
Figure 6.16 : Number of Male and Female CKD/CKDu Patients Reported by Sentinel Sites, 2013 - 2019

Ministry of Health (2019)

CKD in Sri Lanka

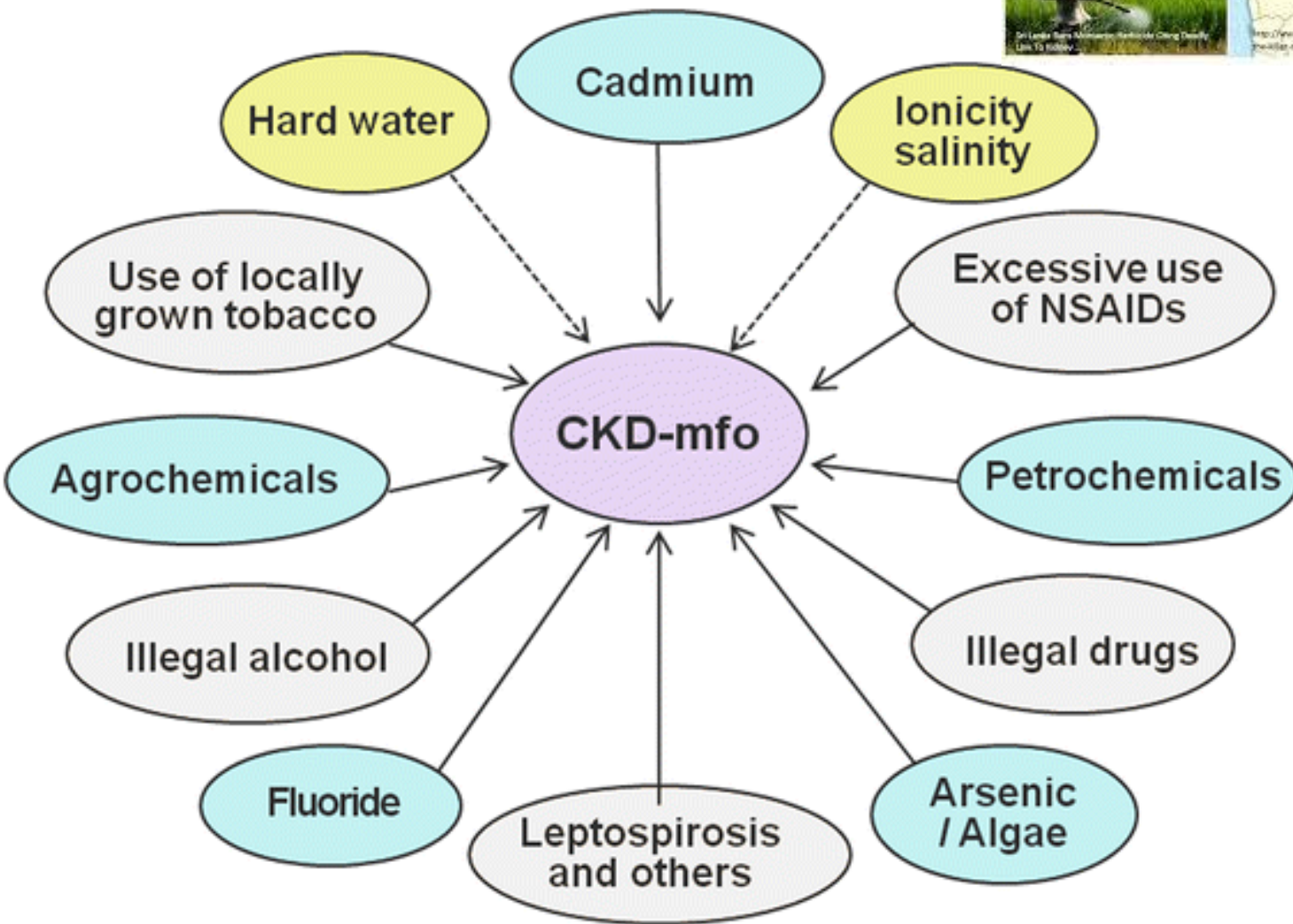
- Common causes- hypertension and diabetes
- In agricultural region- CKD with known and unknown causes
- Prevalence⁴ -15.1%
- Largely affects⁴- young and financially deprived
- More severe stages⁴ - young males [<40years]
- Impact of CKD is detrimental to the health-related quality of life (HRQoL) of individuals and families

⁴Jayatilake, et al. (2013)



Adapted from India environment portal knowledge for change, <http://www.indiaenvironmentportal.org.in>

CKDu - Sri Lanka



Dialysis services - Sri Lanka

Number of nephrologists, n (pmp)	35 (1.6)
Total dialysis population, n	4331
Dialysis modality distribution, n (%)	
In-center HD	3517 (81)
PD	814 (19)
Number of HD machines, pmp	26.5
Number of PD centers, pmp	0.8
HD session frequency, %	
Three sessions per week	<10
Two sessions per week	50
≤1 session per week	40

Explaining Health-related quality of life (HRQoL)

Quality of Life (QoL)

- Broader concept that covers all aspects of life
- Includes aspects of QoL related and not related to health (e.g. cultural, political, or societal attributes)

HRQoL

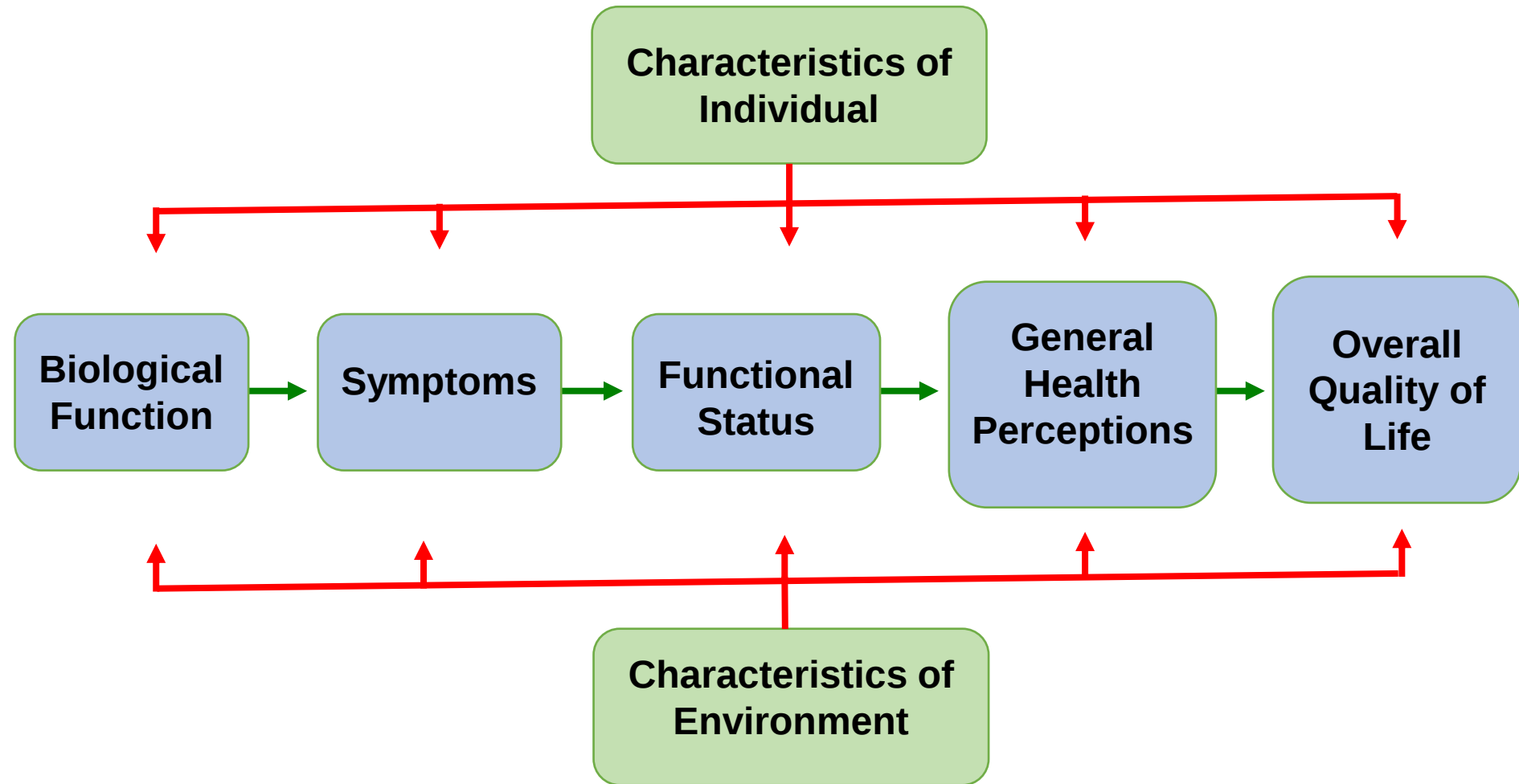
- Narrow the focus to effects of health on QoL
- Includes aspects of QoL related to health, illness, and treatment

(Ferrans, Zerwic, Wilbur, & Larson, 2005; Karimi & Brazier, 2016)

Health-related quality of life

- Dimensions of;
 - physical,
 - psychological,
 - social,
 - spiritual
- aspects of quality of life that are influenced by health and health related events such as diseases and their treatments (Ferrans et al., 2005)

Revised Wilson and Cleary model of HRQoL



Factors contributing to HRQoL

**Reduced
haemoglobin**

Older age

**Receiving
haemodialysis**

**Low income
status**

**Factors
contributing to
HRQoL**

**Female
gender**

**Low
education
level**

**Reduced
physical
functioning**

Comorbidities

**Limited
access to
healthcare**

**Low
spiritual
wellbeing**

**Experiencing
symptoms**

**Advanced
CKD grade**

Impact of CKD on HRQoL

Physical Impact

- Common physical symptoms: fatigue, drowsiness, pain, pruritus and musculoskeletal problems^{5,6}

Psychological Impact

- Common psychological problems: depression, anxiety and body image disturbances^{7,8}

Social Impact

- Common social problems: social isolation, social networking problems, financial problems and family problems⁹

⁵Almutary et al. (2016); ⁶Senanayake et al. (2017); ⁷Senanayake et al. (2018); ⁸Kokoszka et al. (2016); ⁹Al Nazly et al. (2013)

How measure/explore HRQoL

Self-report measures

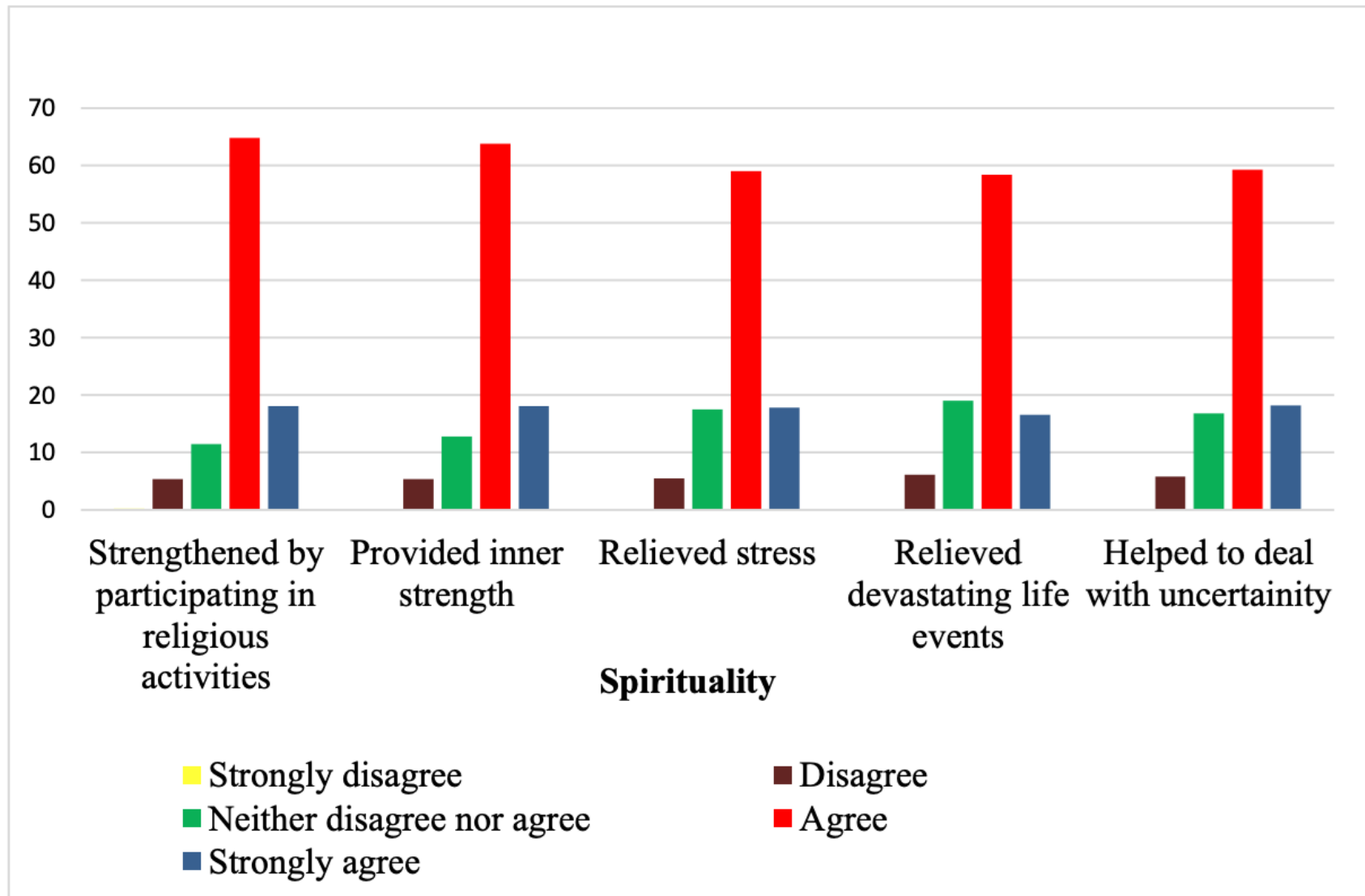
- Kidney Disease Quality Of Life-Short Form (KDQOL-SF™)
- SF-36
- WHOQOL-BREF
- EQ5D3L

Qualitative interviews

CKD Socio-demographic profile

Characteristics	N (%)
Age (years)	Mean=57.1; SD=11.1; Range: 18-84
Gender	
Male	606 (68.4)
Female	280 (31.6)
Education level	
No formal education	48 (5.42)
Up to Grade 8	473 (53.39)
Up to O/L	257 (29.01)
Up to A/L	94 (10.61)
No of comorbidities	
None	181 (20.4)
1	378 (42.7)
2	251 (28.3)
3 or more	65 (7.3)
Distance to the hospital (km)	Median=32; IQR=28; Range: 0.5-272

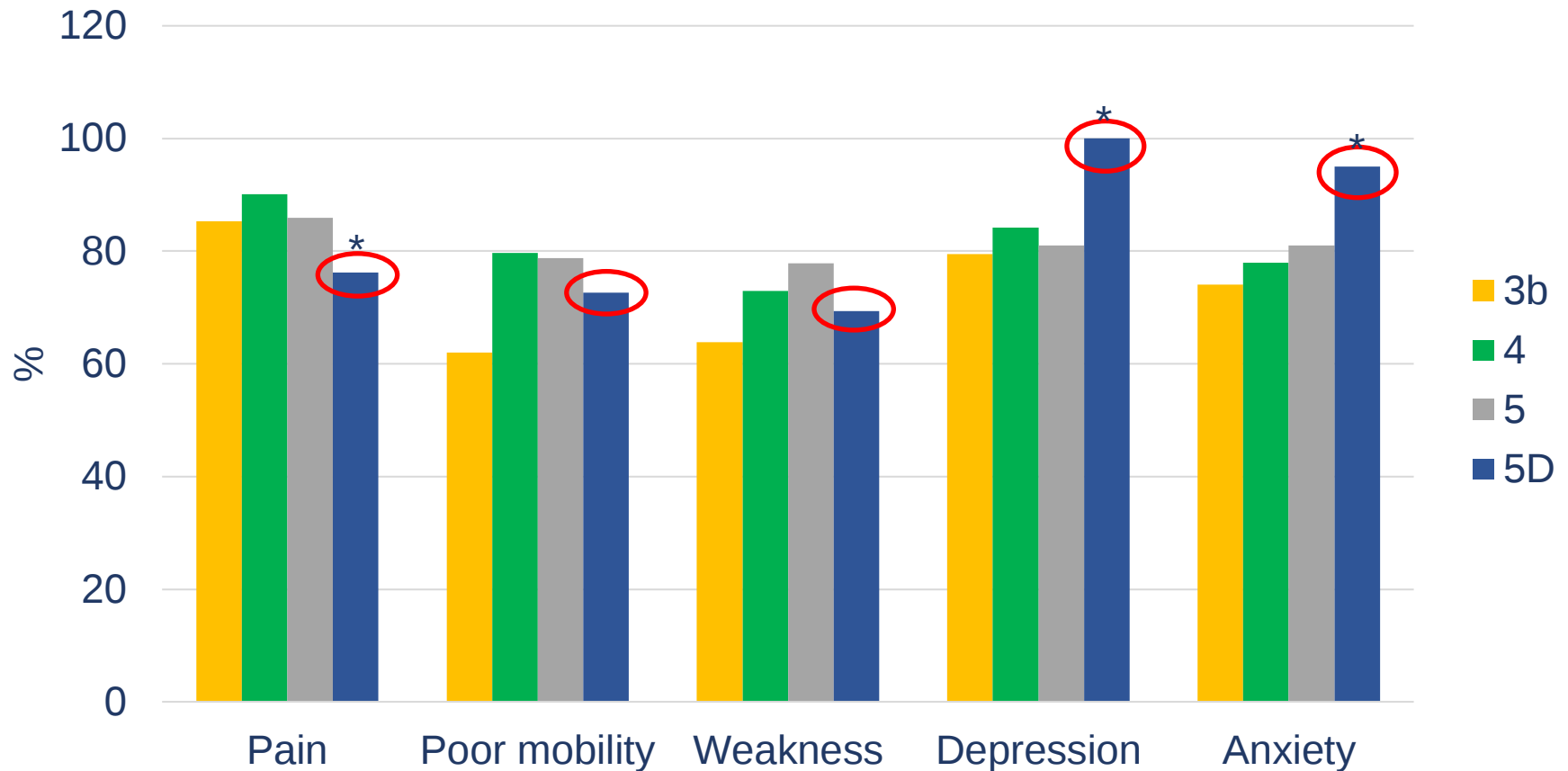
Spiritual beliefs



CKD symptom prevalence and severity (n = 886)

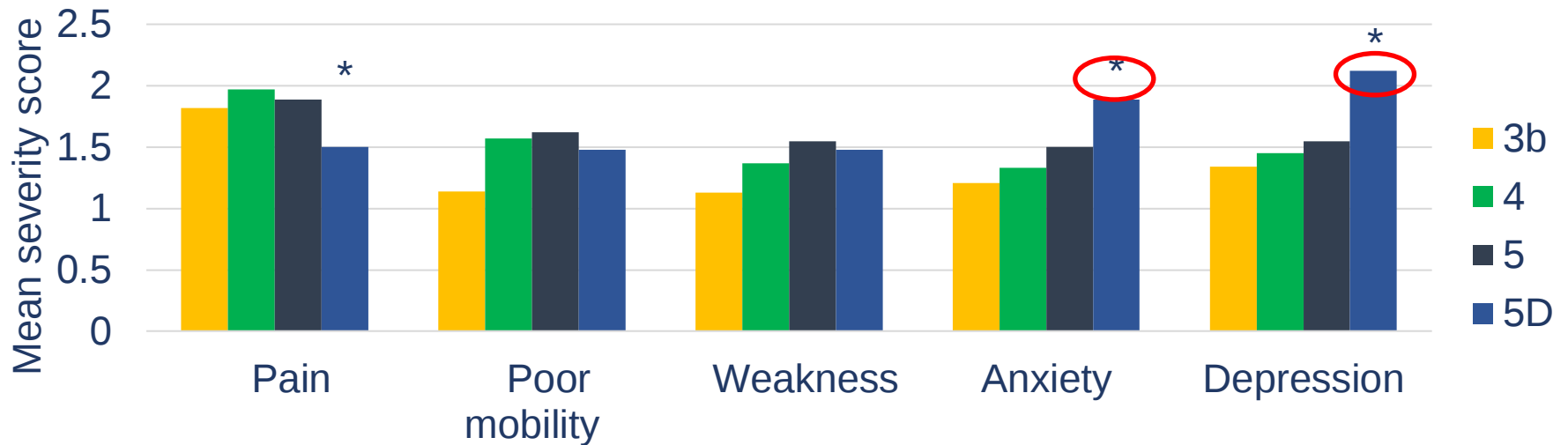
Characteristics	Prevalence N (%)	Severity Mean (SD)
Physical		
Pain	748 (84.42)	1.80 (1.00)
Poor mobility	649 (73.25)	1.45 (1.10)
Weakness	629 (70.99)	1.38 (1.07)
Psychological		
Depression	763 (86.12)	1.61 (0.95)
Anxiety	726 (81.94)	1.48 (1.00)

Most prevalent symptoms by CKD stage (n = 886)



Sig: * $p < 0.001$

Symptom severity by CKD stage (n = 886)



Sig: *p<0.05

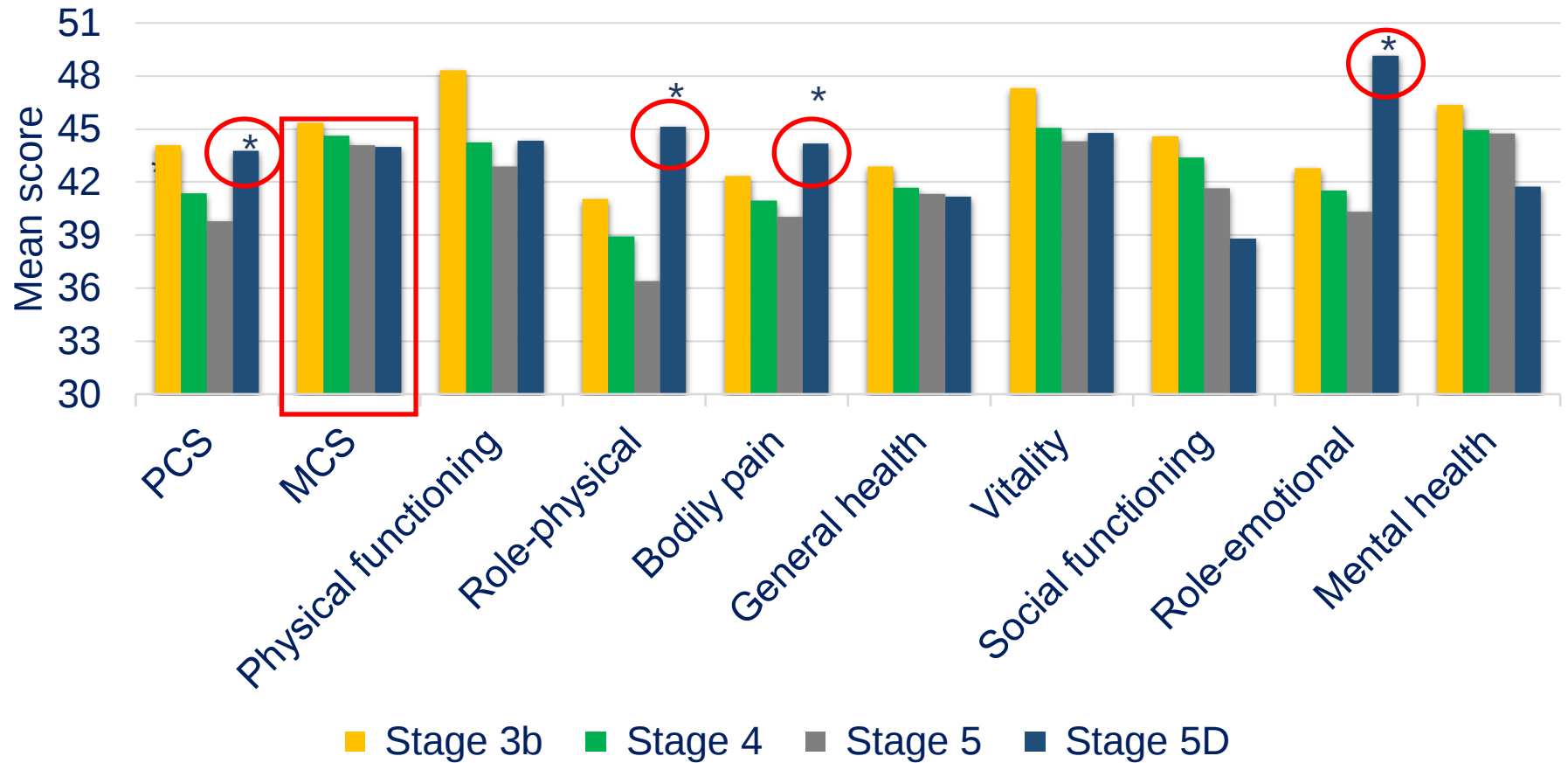
Functional Status, VAS & Index

Dimension		N (%)
Mobility	No problems	372 (41.99)
	Some problems	484 (54.63)
	Severe problems	30 (3.39)
Self-care	No problems	769 (86.80)
	Some problems	89 (10.05)
	Severe problems	28 (3.16)
Usual activities	No problems	434 (48.98)
	Some problems	398 (44.92)
	Severe problems	54 (6.10)
EQ5D3L visual analogue scale (0-100) Mean (SD)		49.14 (23.30)
EQ5D3L index score (-0.73 - 1) Md (IQR)		0.60 (0.32)

HRQoL (n = 886)

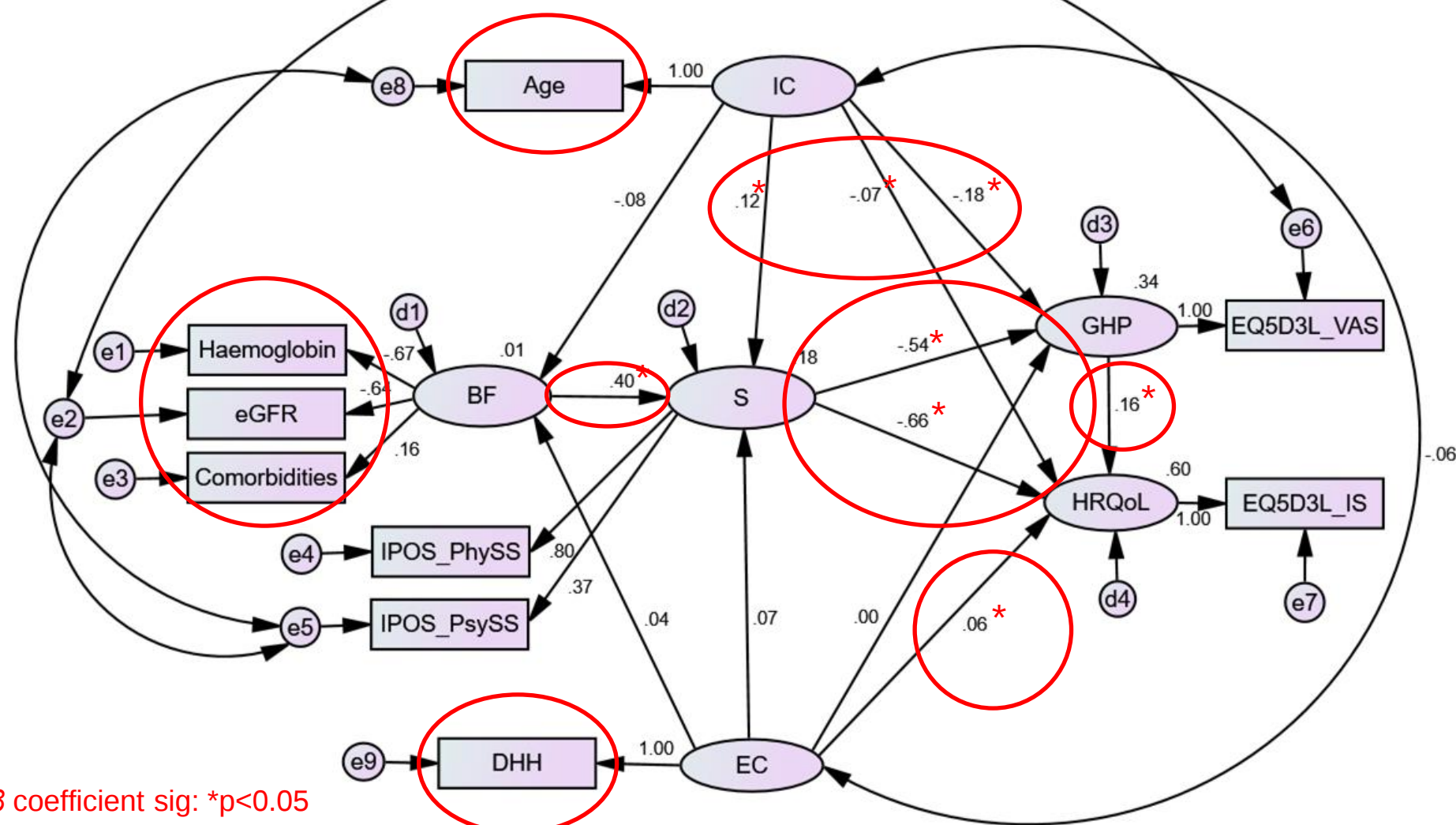
Characteristics (range: 0-100)	Mean (SD)
PCS	42.26 (8.42)
MCS	44.52 (8.37)
Physical functioning	44.95 (9.64)
Role-physical	40.37 (11.29)
Bodily pain	41.88 (8.48)
General health	41.78 (8.12)
Vitality	45.37 (7.56)
Social functioning	42.13 (11.84)
Role-emotional	43.42 (12.67)
Mental health	44.46 (8.71)

HRQoL by CKD stage (n = 886)



Sig: *p<0.05

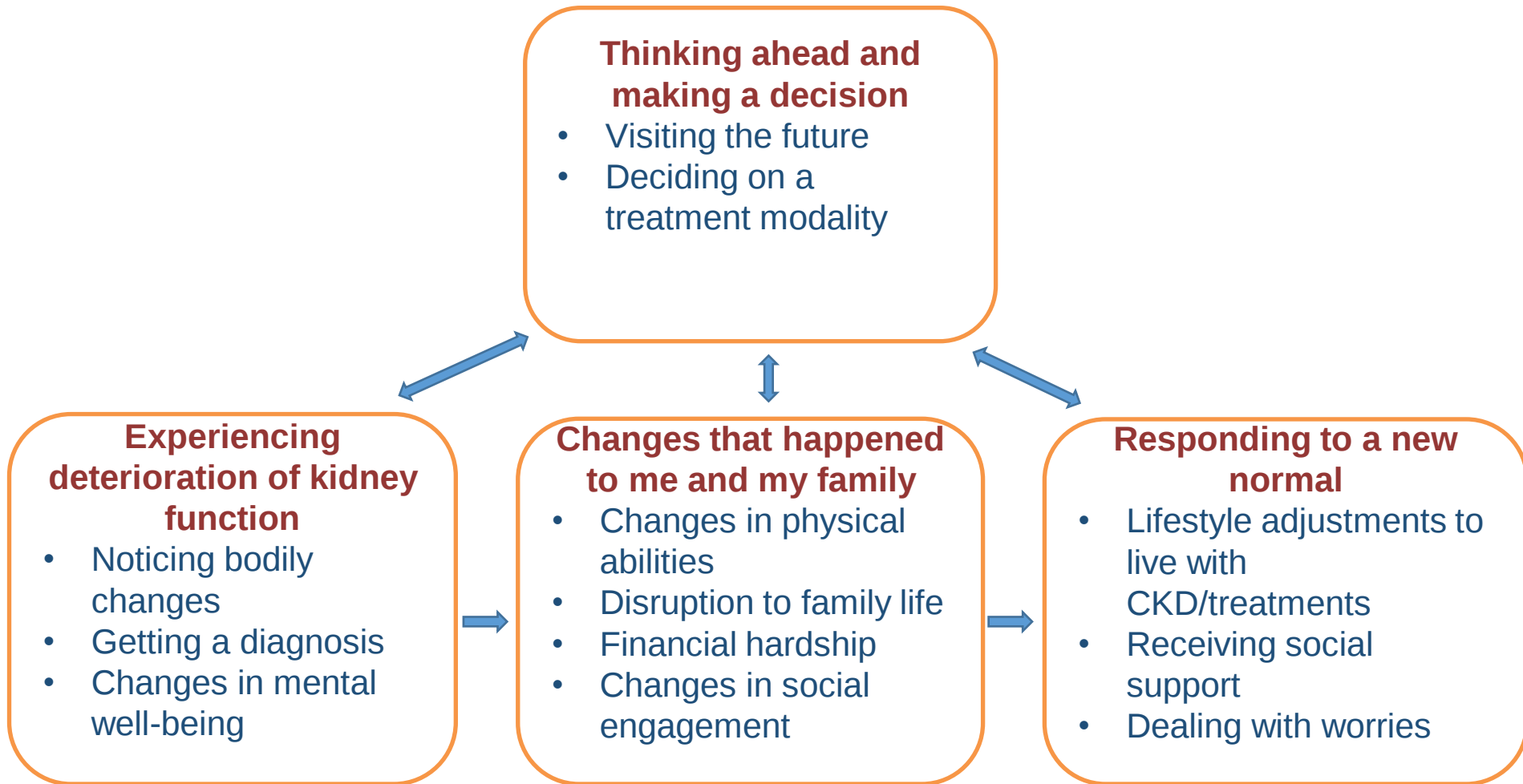
Factors affecting HRQoL



β coefficient sig: *p<0.05

BF: Biological function; S: Symptoms; GHP: General health perceptions; IS: Index score; VAS: Visual analogue scale; IC: Individual characteristics; EC: Environmental characteristics; DHH: Distance to hospital ; PhySS: Physical symptom score; PsySS: Psychological symptoms score

Impact of CKD on HRQoL



Experiencing deterioration of kidney function

[I] don't have [the] body energy that I had [in the past]. ... [I] mostly feel [my] body is weak. [I] lose [the] appetite to eat. [I had] headaches. ... I [would] go to the paddy field, but [I] couldn't work. (Kumara)

Mentally [I] fell [sic] down after [I] got to know [that I had kidney problems]. I was shocked. [I] felt depressed. ... I don't have body energy. So, we are helpless. Can tell [our] worries. But no ending to our worrying. (Kumara)

Changes that happened to me and my family

When [I] was healthy, [I] grew 3–4 acres of corn and 2–2 ½ acres of [rice] paddy. ...[We] lost all of them. [I] don't have [the] energy to do all of them. ... There is half a kilometre to the paddy field. While I go there, I need to rest 4–5 times under trees. [I] can't walk. (Kumara)

Changes that happened to me and my family

He [husband] can't go far to find a new casual job, because of me. In an emergency, I need him to go to the hospital. ... Daughter stopped schooling. She does everything in the home. ... I am restricted to home. People also [do] not invite me to come to community work because I am a sick person. (Kumari)

Responding to a new normal

[I] feel thirst so much. Some days in the past, I [was] brought to the hospital because I lost consciousness. I drank water like that. I couldn't breathe. But now, when I feel thirsty, [I] can stay longer by flushing [my] mouth.

(Sudhara)

I am staying alive because of my father. [My] father had not allowed me to [be] mentally down. He told me to take this easy. (Lakshan)

Thinking ahead and making a decision

“I know this (HD) is a burden. Have to do for my whole life. But thought to live more... because I can do something and help to home... Planned for kidney transplant too. But I couldn’t get from parents. Dad also had kidney problem. Couldn’t get from others. We don’t have money.” (Saman)

Thinking ahead and making a decision

“At last, everybody is dying. [My] plan is to die peacefully.

... See, people come with having needles [sic] to hospital every day or one or two days (for HD). It’s a burden.(Some)

“As of our home condition, it [PD] is difficult to do. ... So, haemodialysis is the best thing I can do... I found a person who [was] willing to give a kidney. But here (public hospital) [they do] not do unrelated transplants. If I want to do it, I have to go to [a] private [hospital]. But we don’t have money to do [it] in [a] private [hospital].” (Dewmi)

Remarks

- Consistent with previous Sri Lankan and other international studies^{5,6,7}, participants experienced a substantial symptom burden.
 - More likely to report symptoms that substantially impacting on their everyday activities such as work tasks.
- As reported in previous studies^{12,13}, HRQoL declined across stages. However, MCS deteriorates across stages slightly.
 - People may change expectations and prospects when adapting to live with CKD over time.¹⁴

⁵Almutary et al. (2016); ⁶Senanayake et al. (2017); ⁷Senanayake et al. (2018); ¹²Aggarwal et al. (2016); ¹³Kefale et al. (2019); ¹⁴Ferrans (2007)

Remarks

- Similar to that of other studies^{9,15}, gender roles within families were disrupted due to a family member having CKD.
 - Spouses were burdened with additional roles such as caregiving and neglected some family responsibilities as caregiving becomes the focal role of family members.
- Participants experienced *financial hardship* owing to their limited ability to work.
 - In contrast to other studies^{9,16}, shifting employment that requires less physical energy is challenging for participants as most of them had performed highly-physically demanding work, such as farming.

⁹Al Nazly et al. (2013); ¹⁵Avril-Sephula et al. (2014); ¹⁶Valsaraj et al. (2014)

Recommendations for improving HRQoL

Practice

- Assess symptoms and HRQoL regularly irrespective of CKD stage.
- Identify people who are at high risk of experiencing poor HRQoL.
- Incorporate renal supportive and palliative care services for routine care delivery.

Policies

- Strengthen social welfare services targeting people with kidney failure who are not on dialysis.
- Collaborate with NGOs with an emphasis on improving HRQoL to better support people with CKD.

Recommendations for improving HRQoL

Research

- Further studies investigating how symptoms and HRQoL change over time
- Future studies that examine the level of caregiver burden in family caregivers of people with CKD
- Experimental intervention studies that focus on improving symptoms and HRQoL of people with CKD

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Thank
you!!

