



# PATIENT AND CAREGIVER PERSPECTIVES ON THE DEFINITIONS AND IMPACT OF TERMS USED TO DESCRIBE KIDNEY HEALTH

Allison Tong for the KDIGO Nomenclature Initiative  
27 – 29 June 2019, Amsterdam, The Netherlands  
#kdigokidneywords & #kdigonomenclature

# DISCLOSURES

- None to declare

KDIGO



The connotation of **end-stage** isn't helpful. Your kidneys **fail** and so will you. By association, your physical existence is failing. Kidneys are **reducing function** might be better. And separate it from the person.

# KIDNEY TERMINOLOGY: PATIENT-CENTERED?



Inconsistent, inaccessible, conceptualized differently between patients and clinicians/researchers



Impair communication and quality of care



Degrading, demoralizing, disempowering >> reduced satisfaction, adherence, autonomy, capacity for decision-making and self-management

KDIGO

## kidney (n.)

early 14c., *kidenere*, unknown origin, perhaps a compound of Old English *cwið* "womb" + *ey* "egg" (shape of the organ).

## renal (adj.)

1650s, from French *rénal* and directly from Late Latin *renalis* "of or belonging to kidneys," from Latin *ren* (plural *renes*) "kidneys,"

## nepbro-

from Greek *nephros* "a kidney" (also of Latin *nefrones*, Old Norse *nyra*, Dutch *nier*, German *Niere* "kidney").



# FOCUS GROUPS

Patients with CKD (all stages) & caregivers

10 focus groups

6 cities

Dallas, Houston, London, Sheffield, Armidale, Sydney

3 countries

US, UK, Australia

Purposive sampling via KDIGO Patient Network + recruiting sites until saturation

# DEFINITION AND IMPACT OF TERMS

**Kidney vs. renal**

**Chronic kidney disease**

**Pre kidney replacement therapy**

**End-stage kidney disease**

**Kidney failure**

**Kidney function: estimated**

**Glomerular Filtration Rate (eGFR);**

**Stages of CKD**

**Remission and relapse**

**Acute kidney injury**

What terms were difficult or challenging – why?

What do they mean to you?

What impacts did/do they have on you?

How would you describe the severity of kidney failure?  
*(including symptoms)*

- Recorded and transcribed
- Thematic analysis (inductive coding, HyperRESEARCH)
- Investigator triangulation
- Member-checking

# PARTICIPANT CHARACTERISTICS (N=67) 54 PATIENTS, 13 CAREGIVERS

Characteristics <sup>1</sup>	N
<b>Sex</b>	
Male	24
Female	43
<b>Country</b>	
US	21
Australia	28
UK	18
<b>Ethnicity</b>	
White	42
African American/British African	15
Asian	4
Other (Hispanic, Aboriginal Australian, Pakistani, Middle Eastern, Indian)	6

Characteristics	N
<b>Age (years)</b>	
18-30	24
31-50	43
51-70	21
>70	28
<b>Education</b>	
Up to 10 <sup>th</sup> grade (16 years)	9
Up to 12 <sup>th</sup> grade (17/18 years)	7
Professional certificate	11
Undergraduate degree	22
Postgraduate degree	18

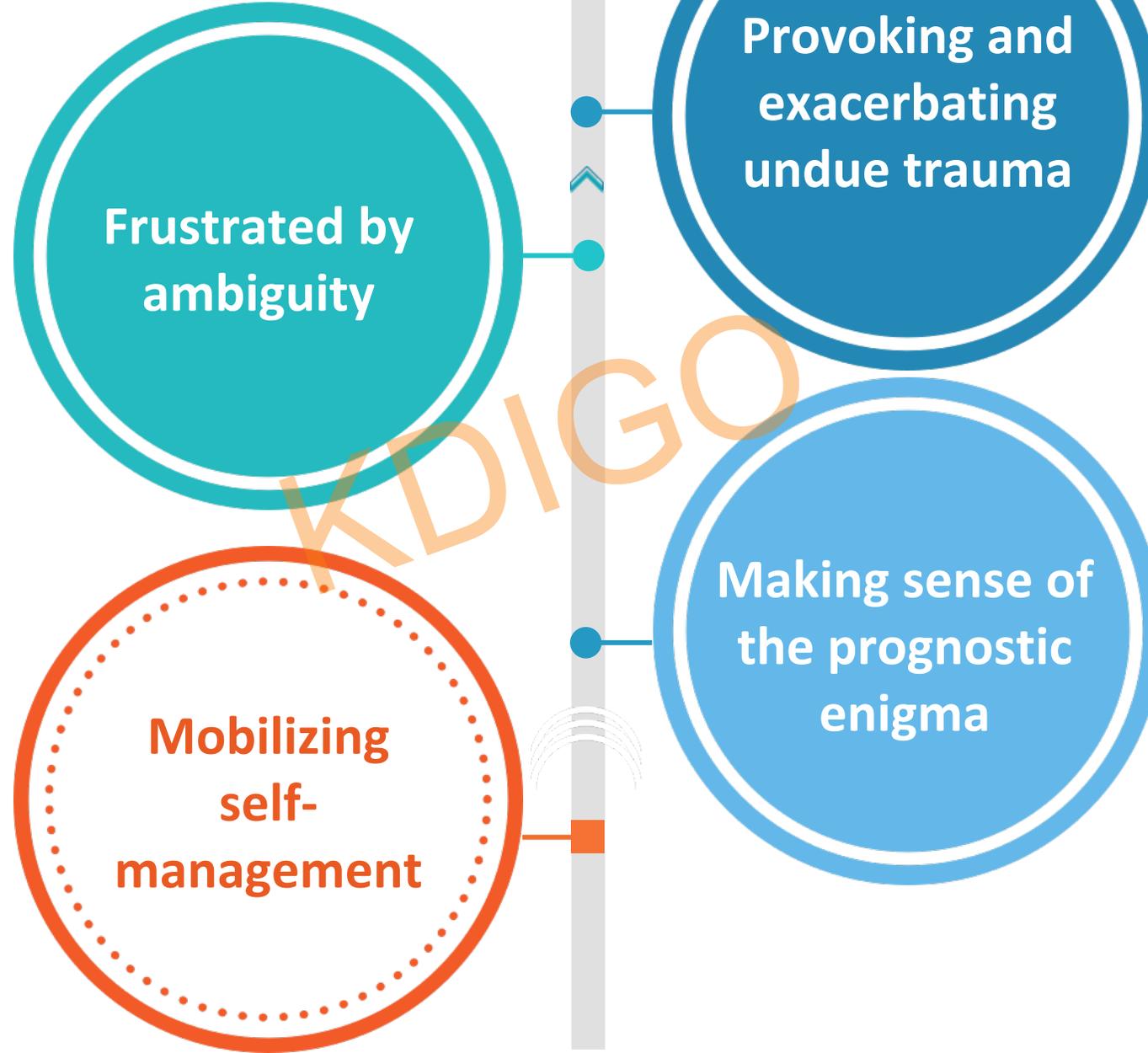
# PATIENT CHARACTERISTICS (N=54)

Characteristics	N
<b>Age at time of diagnosis</b>	
<18	5
18-30	11
31-50	23
51-70	14
<b>Kidney replacement therapy</b>	
None	16
Hemodialysis	14
Peritoneal dialysis	4
Kidney transplant	20

Characteristics	N
<b>Cause/type*</b>	
Glomerulonephritis	19
Hypertension	19
Diabetes	9
Polycystic kidney disease	7
Autoimmune disease	7
Infection	2
Reflux nephropathy	1
Don't know/unknown	3
Other (e.g. AKI, cancer, HUS, amyloidosis)	6

\*Multiple categories could be selected

# PRELIMINARY THEMES



**End-stage** - you're on the cliff, about to fall off. It was quite traumatic and scary.

**Chronic kidney disease.** It's very terminal and final and nothing you can do about it.

I would rather you educate me as to what stage I'm at then using a word that doesn't apply to me such as **pre dialysis**. Dialysis doesn't apply to me now, why do I need to even use the word?

The connotation of **end-stage** isn't helpful. Your kidneys fail and so will you. By association, your physical existence is failing...separate it from the person.

When you get diabetes, they don't say you're **in end stage** pancreas failure. They say, you've got diabetes, you're going to have to use insulin. It's a completely different thing. It's not this 'oh my gosh, my pancreas isn't working'.

## Provoking and exacerbating undue trauma

- Fear of the unknown
- Denoting impending death
- Losing hope in having no treatment options
- Premature labeling and assumptions
- Judgment and failure of personhood

- Confused by medicalized language
- Lacking relevance to personal circumstances
- Baffled by imprecision in meaning
- Uncertainty of what can be controlled
- Opposed to obsolete terms

## Frustrated by ambiguity

I used to get confused about **kidney failure** and my nephrologist would say 'you're not in kidney failure yet, you've got **kidney disease**.' He was using it as the end point kidney failure but I was thinking my kidneys are failing.

When they're putting **GFR** there for you to read and understand they have in parenthesis that if you're African American it's a different number, but they didn't explain why it's a different number.

I never thought of myself as having **end-stage renal failure** because I was on **renal replacement therapy**.

The more technology develops, the less appropriate that word **end** becomes. For the majority of people there are life sustaining treatments: dialysis and transplant.

The **percentage**, this is where I'm confused. If it has to be over an **eGFR** of 60 do you consider 60 100%? I mean what percentage is the hundred percent because it could up to 115?

By sticking with meaningless terms like **Stage 1, Stage 2**. I had no idea what the symptoms of early stage were....[they need to be] educating you on what's going to happen or what could possibly happen to your body and what you'll go through.

I was in **Stage 5** and I still didn't have any symptoms.

**[CKD Stages]** It's good in terms of qualifying where you're at in that. Is it one of those things that you put a time onto though? Because that's the difficulty.

Provoking and exacerbating undue trauma

Making sense of the prognostic enigma

- Conceptualizing level of kidney function
- Characterizing function based on symptoms and life impact
- Predicting progression and need for intervention

Frustrated by  
ambiguity

The words are kind of damaging and painful to the patient, but they're a necessary damage. **End-stage** is a really harsh term, but it's a good term, because you have to drill it home that that really is the last stage of whatever you're going through. If you'd been told that you're a stage V, I would have been like, oh, it's just stage V. I can still reverse it.

If you're saying **pre dialysis** in my mind that says I'm about to go on dialysis but then I'm going to wonder is there something I can do to keep me from going on dialysis if you put it that way.

Understanding the big words, although it can be intimidating, this is your life.

**Mobilizing  
self-  
management**

- Needing to accept the harsh reality
- Prompting and motivating behavior change
- Learning medical terms for self-advocacy

# Selected Quotations for:

1. Kidney failure
2. AKD/AKI
3. CKD
4. Kidney measures

KDIGO

# 1 | Kidney failure

Kidney failure's a good word. Your kidneys have failed. Does it matter what the reason is? They are not working.

**Kidney failure is not transitioned to palliative care, its 'okay, the kidneys have failed but,' you now have several options.**

Kidney failure is **easier to explain** to other people, it means more to other people... If you say end stage they think you're going to fall over dead.

I've never used end stage. They ask me your diagnosis. I say kidney failure.

You have to be at the end of your kidney failure to be called pre-dialysis.

Is it just kidney failure? Because that's the period when your kidneys actually fail. You know, when they're, when, they're no longer able to do the job filtering out the fluids and the toxins.

We would describe someone as end stage lung disease if they're really, really failing, so, on oxygen, imminently needing a transplant. Needing night time ventilation. No one would live with end stage CF for 14 years, you might live for two of three.

What becomes meaningful, because it is kidney failure that we are talking about is, it is that it's a **transition from one form of life where you can exist without either a transplant or some form of intervention to a situation where that's what your life depends on [kidney replacement therapy].**

## 2 | Acute Kidney Injury / Acute Kidney Disease

*\*No targeted recruitment of patients with AKI*

People don't understand also is how severe AKI can be.

That's more of a traumatic injury?

I just presumed it was probably kidney disease that wasn't caused by a progressive illness.

**Or would it be from an injury, like if you got kicked by a horse in your kidney**, or like she was saying, an injury. You come off your motor bike and hurt your kidneys.

I struggle with acute kidney injuries because I think of it as someone **playing rugby or footy and getting a kick in the kidneys and then it bleeds**, like I think acute kidney injuries - like you hear about someone getting those trauma or a fall or a car accident or something. So, when I started reading different things I'm like, that doesn't relate to someone getting hit in the back.

Acute, I really find that is, I think, sudden.

The **kidney injury, as opposed to deterioration, a kidney patient who has been kicked in the back or a car accident or something like that.**

### 3 | Chronic kidney disease

But chronic doesn't mean fatal, it just means it's **impending serious**. It's ever-present sort of thing.

Therefore the chronic part of these diseases bother me in the sense of the longevity of their existence.

I see chronic as things with more serious type term. So it's a qualifying adjective.

The chronic is not a good word to use. Chronic actually sounds terrible right, really bad.

I would prefer 'chronic' any day. End-stage just feels really like, "That's it."

**Chronic is the beginning of the end.**

I've got chronic kidney failure, it's a little bit pointed.

But chronic is not like end stage. End stage has the connotation of death. Chronic just means it quite serious.

I think means you've got something that you will live with and it won't go away. I'd call chronic a scary word, and it's also a clinical word. **It's useful because it's clinical, but it's scary.**

Chronic kidney disease, it was the same as being told you've got terminal cancer, in my head.

Chronic is is a strong word, but it's a irreversible image. You have kidney disease. And then I know if I changed my lifestyle, I can stay in chronic kidney disease.

**I would say utilizing a different term for stage 1 or even 2, would be better than calling it all chronic.**

## 4 | Kidney measures (level of function)

But if the treatment doesn't change, then GFR effectively is you measure where you sit on a spectrum, which is effectively what staging is right?

All the discussions the doctors were having around me, GFR, GFR. I just couldn't understand one bit of it.

So, my GFR basically is telling me how well my kidneys are functioning.

Even when they're putting the GFR out there for you to read and understand they have in parenthesis that if you're African American it's a different number, but they didn't explain why it's a different number, that my muscle mass is different.

I know what GFR means, but I don't know what levels I should have. I always concentrated on knowing my creatinine.

So GFR, I know we need it and we use it, but for me, it's a marker of how things are going.

Stage one is your kidneys are not working, full stop. Stage two is getting bad, stage three is getting to the fistula stage, stage four, dialysis, stage five is not working.

I like it when they say your kidney function is this, rather than say you're at stage four or at a stage. I'd rather them say your kidney function, because you know that they're still working, but you don't know how bad it is. If they say your kidney function is getting worse, then you can deal with that.

**Stages are better than end stage.**

I would rather you educate me as to what stage I'm at then using a word that doesn't apply to me such as pre dialysis. I think it's better to educate me and say you're at stage one. Dialysis doesn't apply to me now, why do I need to even use the word?

They tell me creatinine, and I know what a good boundary is, but I don't understand what it means, or what applies to the function.

# #KDIGO KIDNEY WORDS

ESKD: "Can we ditch 'end-stage'?! ...It may be end-stage for the kidney, not end-stage for our lives." @goKDIGO #kdigokidneywords @winkeldoc @ASLtufts @STMninja @talia\_gutman



**Nikhil Shah** @dr\_nikhilshah · 31/3/19  
Stage 5 - sounds perfect. Patients frequently need numbers to make sense of the disease. "How many stages are there, doc?" Calling it as per CKD stage and using #KFRE to give a reasonable idea of what to expect and when - completes my CKD clinic.

1 comment 1 retweet 5 likes 1 share



**Liz Lightstone** #PeoplesVote · 31/3/19  
@JAPTomlinson @EdwinaB23513542 @NeillDuncan3 #KDIGO Kidney Words #letsditchESKD

1 comment 3 retweets 3 likes 1 share



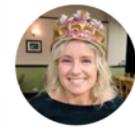
**Tess Harris** @Elektra · 2/4/19  
And 'chronic'. Many people think it means terminal.

1 comment 7 likes 1 share



**Fiona Loud** @FionaCLOUD · 1/4/19  
Replying to @kidneydoc101 @allisontong1 and 26 others  
#Endstage does sound like death is imminent, whereas it's kidney failure now needing treatment as a general description; & as an individual conversation stage 5 could help the discussion of what this actually means to the patient

1 comment 1 retweet 9 likes 1 share



**Maddy Warren** @queenofdial... · 11/4/19  
Replying to @kidneydoc101 @allisontong1 and 26 others  
I had never actually thought about this before... but end stage does sound somewhat dramatic. I think stage 5 works well and would also support pre-dialysis to differentiate those who are imminently choosing/starting their RRT

1 comment 10 likes 1 share





## IMPLICATIONS FOR TERMINOLOGY

- “Ditch end-stage”
- Use kidney not renal
- Avoid pre-dialysis/KRT in describing early CKD
- Kidney failure may be acceptable *(but disentangle this from the person)*
- Chronic requires explanation
- Need for clarity in describing level of function to manage expectations and enable patients to prepare
  - Stages / measures (eGFR)
  - Possible symptoms
  - Need for interventions
  - Timeframe

# SUMMARY

- Some terms are obscure and imprecise
- Provokes and exacerbates undue distress and trauma
- Impairs decision-making, self-management, coping
- Need for consistent and meaningful terminology

