Abstract:

- Chronic kidney disease stages 1 to 4 are asymptomatic health states that are not "disease" according to previously proposed definitions of disease.
- Reduced kidney function levels, currently called chronic kidney disease, are not abnormal in older age groups.
- The label “chronic kidney disease” can be misinterpreted by patients and can be an obstacle to communication.
- Relabelling the stages of "chronic kidney disease" as categories of "kidney age" could improve patient-doctor communication and patient understanding of their diagnosis.
Kidney age, not kidney disease

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Key points

- Chronic kidney disease stages 1 to 4 are asymptomatic health states that are not “disease” according to previously proposed definitions of disease.
- Reduced kidney function levels, currently called chronic kidney disease, are not abnormal in older age groups.
- The label “chronic kidney disease” can be misinterpreted by patients and can be an obstacle to communication.
- Relabelling the stages of “chronic kidney disease” as categories of “kidney age” could improve patient-doctor communication and patient understanding of their diagnosis.
Introduction

While a variety of conditions and syndromes may affect the kidneys over either chronic or acute time frames, the term “chronic kidney disease” (CKD) is used to describe a decrease in the filtration ability of the glomerular capillaries in the kidney. The most prevalent forms of CKD in healthcare systems are typically the asymptomatic stages conventionally termed CKD stage 4 or below (1)(2). Should these asymptomatic stages be called “disease”?

What is meant by “chronic kidney disease”?

In 2002 the US National Kidney Foundation proposed that the term “chronic kidney disease” (CKD) be applied for specific dysfunctions of the kidneys, defined primarily by the glomerular filtration rate (GFR). These guidelines proposed that GFR below 60 ml/min/1.73m$^2$ be considered CKD stage 3; GFR below 30 ml/min/1.73m$^2$, CKD stage 4; and below 15 ml/min/1.73m$^2$, CKD stage 5, with earlier stages (1 and 2) dependent on other evidence of kidney damage such as proteinuria (3). This approach has proved popular, arguably because it can be linked to clear clinical action plans (4). Subsequent guidelines in Canada, the UK and elsewhere, as well as the US, have updated this scheme or proposed modifications for other countries (5). These revisions have often subdivided stage 3 with an additional threshold at 45 ml/min/1.73m$^2$ and/or introduced a secondary classification by proteins in urine, but the emphasis on GFR, often estimated using markers in the blood, has remained constant.

High-quality observational evidence shows a relationship between the stages of CKD and cardiovascular disease as well as end-stage renal disease. A meta-analysis of large cohort studies shows that cardiovascular risk increases with each level of GFR in Table 1, as does risk of future ESRD and risk of acute kidney injury (4,6). These risks also increase with albuminuria, at all levels of GFR except below 15 ml/min/1.75m$^2$ (stage 5). It has been argued that the utility of CKD classification is that it can be linked to a clear action plan (4), although the level of evidence for most of the recommended interventions is not strong (7).

What constitutes a disease?

Smart (8) reviewed four prominent definitions of disease in the philosophy of medicine literature. We considered whether CKD, defined by current thresholds for GFR, is disease by these definitions(9). We found that CKD stage 5 was disease by any definition, because it is associated with harm and statistically rare in any age group. However, earlier stages of CKD are associated with harm as risk factors for further disease (renal or cardiovascular) rather than as disease itself, and whether they are statistically abnormal depends entirely on age(6).

Is the label ‘chronic kidney disease’ helpful to patients or clinicians?

Qualitative data from both clinicians (10,11) and patients (12) have demonstrated that communicating a diagnosis of ‘CKD’ to patients can be uncomfortable and unsatisfactory for all concerned. As soon as the words ‘chronic’ or ‘disease’ are introduced within a consultation, primary care physicians face an uphill battle to retrieve the situation with reassurance (13). Our research (14)
found that the word ‘chronic’ is often misinterpreted by patients as meaning serious, and ‘kidney disease’ can trigger thoughts of dialysis and transplant because people are usually unaware that earlier stages of kidney impairment exist before treatment becomes necessary (see Box 1 quotes 1 & 2).

Clinicians may avoid using the term CKD with their patients or disclosing the diagnosis altogether. Daker-White et al (12) found that 19 of 26 CKD patients interviewed in their study had been told something about their kidney function but only four had been explicitly given a diagnosis of CKD. A study of clinician views found a concern amongst GPs about possibly alarming patients by giving them a disease label when their kidney function was only mildly impaired (11). However, in our study and Daker-White’s (12), non-disclosure of a CKD diagnosis led to some patients finding out about it by accident, such as when consulting a different clinician to usual who assumed they already knew. Such accidental disclosure could lead to shock, anger and upset (see Box 1 quote 3).

Blakeman et al (13) found GPs in their study felt a need to underplay CKD when discussing it with patients. Patient participants in Daker-White’s and our research reported having their kidney function described by doctors in euphemisms such as ‘borderline’, ‘under par’ or ‘leaking kidneys’, rather than as a chronic disease (14).

Regardless of the terms used by professionals to describe early stage CKD to their patients, where it is disclosed it is accompanied by efforts at reassurance that it is nothing to worry about (13). In our research (14), being told not to worry without an accompanying explanation or acknowledgement of patients’ knowledge of other people with severe kidney failure, often failed to provide sufficient reassurance to patients. They were left wanting more information about what might have caused their kidney impairment, the severity of it and what the test results meant, was it reversible and how quickly might it decline to a level where treatment would be needed, what kind of symptoms they should look out for and whether they could do anything to prevent further decline (see Box 1 quote 4).

However, where an explanation was offered patients felt more reassured. Knowing that their kidneys were still functioning sufficiently to not cause them any problems, that they were being regularly monitored and that their test results were satisfactory or stable, were all sources of reassurance, as well as the trust they had in their doctor. Many GPs regard reduced but stable kidney function in elderly patients as a natural result of ageing, and often use this as the basis for the explanation and reassurance they give their patients (11,13). Increasing age was the most common explanation for kidney impairment offered to our patient participants, and in most cases was successful in providing reassurance that they need not worry about it (see Box 1 quote 5).

Is “normal” dependent on age?

An age-related understanding of declining GFR is supported by observational data. Population-based studies consistently show that prevalence of CKD depends strongly on age (15). For example, prevalence increases approximately ten-fold between young adulthood and middle-age in the US Kidney Early Evaluation Program (16) and continues to increase into old age (17). In the Third (US) National Health and Nutrition Survey (NHANES III), Coresh et al. plotted estimated GFR against age (18). The median, and the 5th and 95th centiles declined continuously with age across participants from age 20 to age 90 years.
Kidney age, not kidney disease?

These observations suggest that declining kidney function could better be communicated to patients in the language of “kidney age” rather than “chronic kidney disease”. Similar terminology has been used previously to communicate current health or health risk to patients. Spiegelhalter has previously reviewed concepts of “heart age”, “brain age” and “lung age” that are based on risk of future disease (19). Groenewegen, in a review of proposed “heart age” and “vascular age” metrics, distinguished those based on multivariate prediction of future risk from those based on a single current indicator of vascular health such as carotid intima media thickness (CIMT) (20). In the latter approach, the vascular age of an individual with a given CIMT value is the age at which the median CIMT in a healthy population is this value.

We re-plotted the graphs of Coresh et al., using data from the most recent (2015-6) NHANES survey (Figure 1), reversing the axes to propose a mapping from GFR as an indicator of renal health to age bands. CKD stage 3A for example could be communicated as “kidney age 68 to 77 years”, and stage 3B as “kidney age 77 to 86 years”. The term “chronic kidney disease” would be reserved for those with later stages: in particular, stage 5, or symptomatic stage 4.

Previous authors have argued that failure to account for age in the definition of CKD stages is a “paradox” that accounts for “persistent and serious criticism” of successive CKD classification systems (21). Rather than add complexity to definitions, we hypothesize that adjusting terminology would in many cases avoid unnecessary anxiety, while still signalling concern where appropriate. When estimated “kidney age” is approximately concordant with calendar age, we hope that patients will (as some already do) understand the decline as a natural ageing process. Conversely, when “kidney age” is in excess of calendar age, this should be communicated to patients with discussion about increased risk of future cardiovascular and renal disease. In either case we hypothesize that the language of “kidney age” will avoid misunderstandings that arise from the jargon of “chronic” kidney “disease”.

We argue that the earlier stages (up to stage 4) of “chronic kidney disease” are better described as kidney ageing, but not that there is no such thing as kidney disease. Many pathologies affect the kidney and have existing nomenclature (nephrotic syndrome; polycystic kidneys; etc) beyond the scope of our argument. Proteinuria can occur even with high GFR, and so a normal or low kidney age does not preclude the need to investigate urine protein when indicated (for example, by diabetes or hypertension). Conversely, a decreased GFR, communicated as “increasing kidney age”, remains an indication for further investigation and monitoring; and “kidney age” should be taken into account in management and prescribing decisions.

Next steps

Our proposal is only for a change in terminology, to overcome existing problems with describing declining GFR as ‘disease’. The limitations of existing methods for estimating GFR from serum creatinine apply equally whether the results are communicated to patients as “CKD stage” or “kidney age”. The latter however is likely to have greater resonance with patients, as has the similar concept of “heart or vascular age”. Usefully, existing clinical and prescribing guidelines, clinical action plans and approaches to managing cardiovascular risk would remain unchanged.
In our analysis of previous studies, we have used data from a North American study for convenience; consideration should be given to whether kidney age should be defined separately in different populations: for example, in different ethnic groups. Given a candidate definition of kidney age, further work is then merited to test our hypothesis that this concept has advantages over existing terminology. Interviews or focus groups with patients and health care providers, should investigate the face validity and acceptability of the “kidney age” concept, and explore other alternatives: “age-related” or “age-associated” kidney “dysfunction” or “decline”, for example. If results are encouraging then intervention studies could study the change in terminology as an intervention to improve patient-doctor communication in the first instance, and patient understanding as a consequence. Some hoped-for consequences might be demonstrable on a large scale: for example, an increase in awareness among the proportion of patients on registers (such as the UK CKD register).

The required change in language would need to be widespread, ideally reaching clinical guidelines (and software) as well as information materials for the public and for patients, but it would be minor, in that it does not in principle require changes to practice, or to the content (as opposed to the language) of clinical guidelines. Potential advantages include: better understanding in those with impaired but age-appropriate kidney function; similarly, readier understanding in those with age-inappropriate kidney function; hence, greater readiness of family clinicians to discuss declining GFR with both groups; avoidance of confusion or distress arising from the jargon term “chronic”; reservation of the “disease” for the stages of kidney dysfunction that are associated with direct harms – and for which treatment exists. Although these are consistent with the qualitative research findings discussed above, we list them as a potential, rather than proven, advantage, and hope for further development and testing of the kidney age concept in the near future.
Table 1. Definitions of chronic kidney disease according to glomerular filtration rate (GFR) by the Kidney Disease Outcome Quality Initiative (KDOQI) of the US National Kidney Foundation.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
<th>GFR (mL/min/1.73m²)</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Kidney damage with normal or elevated GFR</td>
<td>≥90</td>
</tr>
<tr>
<td>2</td>
<td>Kidney damage with mild decrease in GFR</td>
<td>60-89</td>
</tr>
<tr>
<td>3*</td>
<td>Moderate decrease in GFR</td>
<td>30-59</td>
</tr>
<tr>
<td>4</td>
<td>Severe decrease in GFR</td>
<td>15-29</td>
</tr>
<tr>
<td>5</td>
<td>Kidney failure</td>
<td>&lt;15 (or dialysis)</td>
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* Modified in 2014 to distinguish stage 3a, defined by GFR between 45 and 59 mL/min/1.73m², from stage 3b, defined by GFR between 30 and 44 mL/min/1.73m².
Figure 1. Percentiles of age by (estimated) GFR (mL/min/1.73m²). National Health and Nutrition Examination Survey 2015 to 2016. Red line denotes average (median) age for a given GFR and blue lines denote 5th and 95th centiles.


(8) Smart B. Concepts and causes in the philosophy of disease.

(9) Do concepts of disease apply to "chronic kidney disease"? Conference presentation. Too much medicine: exploring the relevance of philosophy of medicine to medical research and practice.; 19-20 April 2017; .


(19) Spiegelhalter D. How old are you, really? Communicating chronic risk through 'effective age' of your body and organs. BMC Med Informatics Decis Mak 2016;16(1).


Box 1. Patient quotes (all from our own research (12))

Quote 1

I couldn’t understand how I could be described as having chronic kidney disease when it had only just been discovered. ‘Chronic’ to me means – well maybe mistakenly – that I’ve had it for a long long time ... they keep using this word ‘chronic’ and I think the word ‘chronic’ makes it sound worse than what it is, to me anyhow.

(Eric, aged 79)

Quote 2

One of my older brothers – he had kidney problems when he was quite young. And then he had kidney failure completely and he had a transplant done and that worries me a little bit... we’re both exactly the same build and everything. He had bowel cancer and it seems to me everything he got, I get.

(Bill, aged 71)

Quote 3

I went for my normal routine check up to have blood tests and blood pressure and water and that. And my diabetic nurse came in with the nurse that was doing the test to send away to have the results come back and she asked me if I’d like to join this programme that you’re running. And I asked her what it was about and she explained in my language that it was due to kidney problems. And I went into defensive mode. I said, “No, I’ve never had kidney problems. I haven’t got kidney problems with diabetes. It’s you know, I’ve been told everything was all right.” And then she told me that I had a kidney problem that was being monitored regularly and I asked her, “How long have I had it? Can you tell me when it was diagnosed?” And she said in 1997, which was an absolute shock. [laughs] We had a short discussion because she had to go and see to other patients and she was under the impression I knew. But my daughter and I had been to the doctors when the results came through before, and I’d asked about kidneys and they’d always said, “No, they’re fine.” So this really was a bit of a... a shock. I laughed about it at first. I thought that it was a bit of a mix up. But now I understand there isn’t but yet I haven’t had it explained to me quite what it entails or what it’s about.

(Joan, aged 70)

Quote 4

I want to know why they’re failing, that’s what I want to know. I mean I’m not a drinker, I don’t drink, so whether it is the medication or whether old age, well, she hasn’t explained. She just, as I say, she [general practitioner] has just said that my kidneys aren’t working as they should and I’m almost living on one kidney, but I wasn’t to worry because hundreds of people live on one kidney. But then it starts alarm bells ringing doesn’t it? Why are your kidneys failing; what have I done to make them fail? Is it my lifestyle, is it tablets? I mean it can’t be drink because I don’t drink; is it coffee? You don’t know, do you?

(Elizabeth, aged 74)

Quote 5

But as far as an explanation of why the kidneys aren’t working perfectly, she [the GP] did, most recently, tell me that kidney function decreases as you get older, and I accept that as being the case like everything else. You get older you lose your memory and things.

(Eric, aged 79)
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