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Helping people to live well with chronic kidney disease

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Abstract

Reduced glomerular filtration rate and presence of albuminuria are both associated with increased risk of several poor outcomes. People with chronic kidney disease also commonly suffer from lower quality of life than their age-matched peers. The experiences reported by patients with chronic kidney disease include being shocked by the diagnosis, being uncertain about the cause and worrying about progression and future treatment. Issues such as depression, pain and fatigue are common in people with chronic kidney disease. Helping people to live well with a long-term condition like chronic kidney disease should include efforts to reduce the risk of adverse events occurring in the future, and consider what can be done to enhance quality of life now. Clinicians can help by being aware of the patient perspective, communicating clearly and recommending interventions that reduce future risk as well as recognising and treating symptoms. Assessing overall treatment burden is an important component of management and non-pharmacological interventions that may improve mobility, strength and pain should be considered.

Key words: Chronic; Quality of life; Renal insufficiency; Risk

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Introduction

This article considers some of the implications of having chronic kidney disease, discusses what is known of the experience of the condition from the patient perspective and, based on these issues, addresses how clinicians can best help people to 'live well' when they have the diagnosis.

In the last decade chronic kidney disease has courted a degree of controversy. It has been included in debates on 'too much medicine' with concerns about over-labelling individuals with a 'disease' and the resulting burden and costs of clinical assessment, investigations and 'unnecessary' treatment for both patients and health services (Moynihan et al, 2013). On the other hand, it is clearly a condition with a wide spectrum of severity, from a minor degree of reduced kidney function, often identified as an incidental finding, to life-changing end-stage kidney disease requiring complex decisions about kidney replacement therapy (kidney replacement therapy, dialysis or transplantation) or conservative care. And it is not just end-stage kidney disease that presents clinical challenges – there is now incontrovertible evidence that any degree of kidney dysfunction or damage is strongly associated with poor outcomes for patients. Large, international meta-analyses of both high risk and general population cohort studies have shown that any degree of low estimated glomerular filtration rate and albuminuria are both independent risk factors for poor outcomes including all-cause and cardiovascular mortality (Chronic Kidney Disease Prognosis Consortium, 2010; van der Velde et al, 2011), cardiovascular disease (Matsushita et al, 2015), progression of chronic kidney disease, hospitalisation and acute kidney injury (Astor et al, 2011; Gansevoort et al, 2011; Grams et al, 2018).

This has understandably left some clinicians uncertain about how best to approach management, particularly in patients with early or moderate chronic kidney disease. Should the condition be played down as 'not that important' and possibly not even disclosed to patients as it may cause unnecessary distress? Or should its identification be prioritised with a view to early intervention to allow the best possible opportunity for the prevention of progression to end stage disease or other complications?

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This article unpicks some of these issues and provides some useful strategies with practical clinical application, while keeping the person with chronic kidney disease at the centre of the discussion.

Classification and epidemiology of chronic kidney disease

The Kidney Disease Improving Global Outcomes (KDIGO) risk classification of chronic kidney disease includes both reduced excretory function (by estimated glomerular filtration rate) and kidney damage (by presence of albuminuria) (KDIGO, 2013). Estimated glomerular filtration rate is categorised into six stages – G1 ($\geq$90 ml/min/1.73 m^2) to G5 (estimated glomerular filtration rate <15 ml/min/1.73 m^2), and albuminuria into three groups (A1 reflecting urine albumin:creatinine ratio <3 mg/mmol to A3 indicating urine albumin:creatinine ratio $\geq$30 mg per mmol) (KDIGO, 2013).

Chronic kidney disease is common; prevalence in England is estimated at between 12% and 13% of the population, based on the nationally representative Health Survey for England (and including both estimated glomerular filtration rate and urine albumin:creatinine ratio), rising to over 30% among people over 75 years (Fraser et al, 2014). While it is important to note that this was based on a single measure of estimated glomerular filtration rate, and studies basing their chronic kidney disease definition on two values of estimated glomerular filtration rate at least 90 days apart, as per KDIGO guidelines, have found lower prevalence, the prevalence of estimated glomerular filtration rate <60 ml/min/1.73 m^2 was still 16% among people aged over 60 years in the Oxford Renal Cohort Study (Hirst et al, 2018). Future incidence and prevalence is likely to reflect a balance between the growing, ageing population and increasing prevalence of obesity and type 2 diabetes, against improving hypertension control and falling smoking prevalence (Hounkpatin et al, 2014). As these population demographics and risk factors change over time, it is also likely that patients who have chronic kidney disease as one of their health problems will be increasingly complex and multimorbid (Fraser et al, 2015; Fraser and Taal, 2016; Tonelli et al, 2018). Given this context, the main focus of this article is on how clinicians can help people with chronic kidney disease generally, rather than on the specific context of people on kidney replacement therapy, which has its own unique challenges and requires specialist input. The overall aim is to understand how the most holistic care can be offered to people with the condition.

What is meant by ‘living well’?

Before continuing, it is worth considering what is meant by living well. Arguably, clinical interventions in any chronic condition could be considered as having one of two broad aims:

1. To reduce the risk of adverse events occurring in the future
2. To enhance quality of life now.

The first might include things like prescribing statins for secondary prevention of cardiovascular disease, or inhaled steroids to prevent acute exacerbations of asthma. The second may focus on trying to alleviate unpleasant symptoms, such as addressing pain or breathlessness, providing rehabilitation to improve function, or adjusting medications that are causing side effects. This framework is used to consider how, within the specific context of chronic kidney disease, clinicians can advise patients on living well by reducing the risk of various adverse future events and optimising quality of life. In order to do this, it is important to understand the implications of having chronic kidney disease.

Living with chronic kidney disease: the patients’ perspective

Awareness of kidney function and chronic kidney disease

In understanding patients’ experiences of living with chronic kidney disease, it is worth bearing in mind the public understanding of kidneys and their function. In 2014, as part of the UK ‘Think Kidneys’ programme, over 2000 UK residents were surveyed on their knowledge and understanding of kidneys, with results weighted for key demographic characteristics. This survey found that only 51% of people knew that kidneys make urine (the figure was 59% among graduates), 60% knew that the kidneys help remove waste, 12% knew that kidneys have a role in processing medicines, only 1% thought that smoking endangers kidney health and more than 60% thought alcohol endangers kidney health (Slevin and Taylor, 2015).

It is also worth remembering that a significant proportion of people with mild or moderate chronic kidney disease may be unaware that they have the condition. In the Renal Risk in Derby study (a cohort of about 1700 people with chronic kidney disease stage 3 recruited from primary care), 41% were unaware of their chronic kidney disease diagnosis at baseline (McIntyre et al, 2012).

Patients' experience of living with chronic kidney disease

A systematic review and meta-ethnography of 10 qualitative studies involving a total of 596 patients with non-kidney replacement therapy requiring chronic kidney disease identified seven themes that express the experience of being diagnosed and living with the condition (Teasdale et al, 2017). These are summarised in Table 1 and show that many patients find receiving the diagnosis difficult, worry about its causation and have important concerns about future risk. They are often concerned about the way in which chronic kidney disease will limit their life and feel that they have insufficient information with which to address these concerns. A further level of complexity in identifying the best ways of supporting patients is the relatively high prevalence of low health literacy, particularly among some more vulnerable groups of people with chronic kidney disease (Taylor et al, 2017).

Table 1. Summary findings of a meta-ethnography of the experience of being diagnosed with and living with chronic kidney disease

Theme	Summary aspects of the theme
A challenging diagnosis	Feeling well and asymptomatic when first diagnosed Feelings of shock and incomprehension about the diagnosis Uncertainty about chronic kidney disease permanence
Diverse beliefs about causation	Believing chronic kidney disease was a result of their own actions, eg poor eating habits and alcohol or long-term medication use Attributing chronic kidney disease to external factors such as heredity or as the result of having other conditions such as diabetes
Anticipated concerns about progression	Concerns about future treatment Anticipated social and financial burden Being unable to continue working and/or inability to care for significant others
Delaying disease progression	Making adjustments to daily life to try and delay disease progression, eg lifestyle changes
Unmet informational needs	Common viewpoint: participants believed they had received insufficient information about chronic kidney disease and its progression from health professionals Some perceived this as a deliberate attempt to withhold information
Psychosocial impact	Loss of freedom and restricted choices (particularly in people with chronic kidney disease stage 5) as a result of treatment regimens, fatigue, dietary restrictions and/or dependence on others
Adjustment to life with chronic kidney disease	Greater involvement with decision making Importance of community and/or social support Trying to live life to the full, 'carry on as normal', be positive

From Teasdale et al (2017)

It is important to be mindful of this patient perspective when considering the more clinical implications of having chronic kidney disease.

What are the implications of having chronic kidney disease?

Chronic kidney disease and future risk

It is beyond the scope of this article to discuss all of the measures used to assess and quantify each of the following risks, attributes and outcomes but it is helpful for all health carers to have a basic understanding (Kazmi et al, 2018).

Mortality and end-stage kidney disease

As mentioned above, the two most important risk factors for mortality associated with chronic kidney disease are reduced glomerular filtration rate and albuminuria, although the risk varies with age (Table 2). The relative risk of mortality for people with reduced glomerular filtration rate remains statistically significantly higher than for their peers with better renal function, although it decreases with increasing age. However, the absolute risk associated with having reduced glomerular filtration rate increases considerably. There is a similar picture for albuminuria.

For any outcome in chronic kidney disease, there are issues of competing risks. For example, if assessing the risk of progression to end-stage kidney disease, account needs to be taken of the competing risk of death (ie that individuals die before they ‘have the opportunity’ to experience the outcome of end-stage kidney disease). Bansal et al (2015) developed a score to predict risk of mortality among older patients with chronic kidney disease. The model includes age, sex, race, estimated glomerular filtration rate, urine albumin:creatinine ratio, smoking, diabetes mellitus and history of heart failure and stroke. Similarly, Tangri et al (2011) developed a kidney failure risk equation for prediction of progression to end-stage kidney disease. Adoption of these risk scores to evaluate the relative risks of death vs end-stage kidney disease has been proposed by the European Renal Best Practice Group as part of a Clinical Practice Guideline on the management of older patients with chronic kidney disease stage 3b or higher (Farrington et al, 2017).

Cardiovascular disease and cardiovascular death

For the majority of people with chronic kidney disease, risk of cardiovascular disease is substantially higher than risk of end-stage kidney disease (Chronic Kidney Disease Prognosis Consortium, 2010; van der Velde et al, 2011; Matsushita et al, 2015). Following evidence that they improve prediction accuracy, estimated glomerular filtration rate and urinary albumin:creatinine ratio are recommended to be included in cardiovascular risk

Table 2. Variation in relative and absolute mortality risk by age for people with chronic kidney disease

	Reduced glomerular filtration rate: Estimated glomerular filtration rate 45 ml/min/1.73 m^2 *vs* 80 ml/min/1.73 m^2		**Albuminuria: Urinary albumin:creatinine ratio 300 mg/g *vs* 10 mg/g**	
Age (years)	**Relative (adjusted hazard ratio (95% confidence interval))**	**Absolute (excess deaths per 1000 person-years (95% confidence interval))**	**Relative (adjusted hazard ratio (95% confidence interval))**	**Absolute (excess deaths per 1000 person-years (95% confidence interval))**
18–54	3.50 (2.55–4.81)	9.0 (6.0–12.8)	2.53 (2.13–3.03)	7.5 (4.3–11.9)
55–64	2.21 (2.02–2.41)	12.2 (10.3–14.3)	2.30 (1.84–2.88)	12.2 (7.9–17.6)
65–74	1.59 (1.42–1.77)	13.3 (9.0–18.6)	2.10 (1.83–2.44)	22.7 (15.3–31.6)
≥75	1.35 (1.23–1.48)	27.2 (13.5–45.5)	1.73 (1.45–2.05)	34.3 (19.5–52.4)

From Hallan et al (2012)

prediction models (Matsushita et al, 2015). The CKD Prognosis Consortium has developed a risk scoring tool that simultaneously estimates the risk of death, cardiovascular events and end-stage kidney disease, although this is applicable only to persons with chronic kidney disease category G4 (Grams et al, 2018).

Hospitalisation

A large UK study showed that among 15 336 participants aged 75 years and older from 53 UK general practices, dipstick-positive proteinuria and/or estimated glomerular filtration rate <30 ml/min/1.73 m^2 was associated with an increased risk of single and multiple hospitalisation after adjustment for age, sex and cardiovascular risk factors (Nitsch et al, 2011). After full adjustment, the hazard ratio for hospitalisations during less than 6 months of follow-up was 1.66 (95% confidence interval 1.21–2.27) for estimated glomerular filtration rate <30 ml/min/1.73 m^2 compared with estimated glomerular filtration rate of 60–74 ml/min/1.73 m^2. Dipstick-positive proteinuria was also associated with an increased hazard ratio for admission (1.29; 95% confidence interval 1.11–1.49) (Nitsch et al, 2011).

Acute kidney injury

A further CKD Prognosis Consortium study, involving eight general-population cohorts (1 285 049 participants) and five chronic kidney disease cohorts (79 519 participants), showed that lower estimated glomerular filtration rate and higher urine albumin:creatinine ratio were both strongly and independently associated with acute kidney injury (Grams et al, 2015). Compared with estimated glomerular filtration rate of 80 ml/min/1.73 m^2, the adjusted hazard ratio of acute kidney injury at estimated glomerular filtration rate of 45 ml/min/1.73 m^2 was 3.35 (95% confidence interval 2.75–4.07) and compared with a urine albumin:creatinine ratio of 5 mg/g, the risk of acute kidney injury at urine albumin:creatinine ratio of 300 mg/g was 2.73 (95% confidence interval 2.18–3.43). Older age was also associated with higher risk of acute kidney injury (Grams et al, 2015).

Inequalities

Age is one of the key inequalities in chronic kidney disease. It is beyond the remit of this article to describe all aspects of chronic kidney disease inequality, but they include greater prevalence in lower socioeconomic groups, variation in prevalence and progression by ethnicity and sex. More women have kidney disease, but more men start dialysis, and people from south Asian and black backgrounds are more likely to start dialysis than people from white backgrounds (Caskey and Dreyer, 2019).

Comorbidities

As suggested above, comorbidities are common in people with chronic kidney disease and are associated with polypharmacy (Fraser et al, 2015). They are an important determinant of adverse outcomes and this is true not only for the ‘usual suspects’ expected in the context of chronic kidney disease – diabetes and cardiovascular conditions – but also for conditions that have been considered ‘discordant’, such as dementia and cancer (Tonelli et al, 2015).

Some specific comorbidities and other attributes are considered below.

Quality of life

Quality of life tends to be poorer for people with chronic kidney disease than their general population peers (Perlman et al, 2005). Quality of life scores also tend to decline with decreasing glomerular filtration rate (Perlman et al, 2005; Mujais et al, 2009). In a large North American cohort study of people with chronic kidney disease 3–5, other associations of poor quality of life included being female and having comorbidities (particularly diabetes and cardiovascular disease, including heart failure) (Mujais et al, 2009). It is notable that physical functioning scores also declined progressively with more advanced stages of chronic kidney disease in this cohort and that lower quality of life was associated with anaemia and beta blocker use (Mujais et al, 2009). Decline in functional capacity, often linked to the presence of comorbidities, is also associated with worsening renal function (Chin et al, 2014).

Pain

The prevalence of chronic pain in people with chronic kidney disease stages 1–4 has been estimated at about 70% in two American studies, with musculoskeletal the most common cause (Davison et al, 2014). However, there is wide variation in prevalence estimates, potentially dependent on population studied and definition of pain. In the UK, a cohort study using repeat pain medication to define pain among people with chronic kidney disease stage 3 identified a prevalence of about 30% (Fraser et al, 2015). In the Tonelli et al (2015) large database study from Canada (*n*=530 771 with chronic kidney disease), where 'chronic pain' was based on clinical codes, the prevalence of painful condition was nearer to 10%.

Depression

Depression is also common among people with chronic kidney disease. In a review of eight studies of people with chronic kidney disease stage 2–5 (total *n*=11 501), depression prevalence varied between 21% and 47% (Shirazian et al, 2017). Outcomes associated with depression in these studies included hospitalisation, end-stage kidney disease, acute kidney injury, worse quality of life, faster/greater decline in glomerular filtration rate and mortality (Shirazian et al, 2017). The Tonelli et al (2015) study, where again depression was based on International Classification of Diseases (ICD) codes, identified a depression prevalence of 11.3% and in the Renal Risk in Derby study, where depression was based on antidepressant medication prescription, it was even lower at about 5% (Fraser et al, 2015). These latter studies, with more restricted definitions, are almost certainly an under-estimation of the true prevalence. The prevalence reported in the eight-study review is not dissimilar to estimated prevalence in the England general population, reported to be about 27% among people aged over 65 years (Feng et al, 2015).

Functional limitation

Chronic kidney disease seems to be associated with an adverse impact on activities of daily living. For example, a Korean cohort of 984 people with varying degree of renal function impairment followed for 5 years found that the incidence of decline in activities of daily living and instrumental activities of daily living (activities that support independent living) was 13%, 12.5% and 29.5% in participants who showed improvement, no change and decline in glomerular filtration rate respectively (*P*=0.01) (Chin et al, 2014). An Alabama cohort exploring the impact on instrumental and basic activities of daily living (self-care tasks) conducted over 2 years had similar findings, with adjusted odds ratios for chronic kidney disease vs non-chronic kidney disease decline in instrumental and basic activities of daily living of 1.83 (95% confidence interval 1.06–3.17, *P*=0.03) and 2.46 (95% confidence interval 1.19–5.12, *P*=0.02) respectively (Bowling et al, 2011).

Frailty

Frailty may be more common among people with chronic kidney disease than people without. Among 5808 adults in a cross-sectional American study, prevalence of frailty was 15% in people with chronic kidney disease vs 6% in those without (*P*<0.001). After multivariable adjustment for comorbidity, chronic kidney disease remained significantly associated with frailty (odds ratio 1.76; 95% confidence interval 1.28–2.41) (Shlipak et al, 2004). More work is needed on the relationship between chronic kidney disease and frailty to explore the direction of causality.

Fatigue

Fatigue is common, particularly among people with advanced chronic kidney disease (Artom et al, 2014). Prevalence estimates vary between about 40% and 90% depending on stage of chronic kidney disease, measurement instruments used and treatment modality (for those on dialysis).

Treatment burden and polypharmacy

Treatment burden can be defined as the workload of healthcare, or the 'work of being a patient', and its impact on patient functioning and wellbeing (Shippee et al, 2012; Sav et al, 2015). Activities such as taking and managing multiple medications, organising and

Table 3. Things that people with chronic kidney disease and clinicians can do to support 'living well' with the condition

	Patients	**Clinicians**
Reducing future risk	Undertake monitoring, particularly of their own blood pressure	Regular monitoring, particularly albuminuria, estimated glomerular filtration rate and blood pressure
	Lifestyle measures: dietary sodium restriction, weight loss, exercise	Cardiovascular risk assessment (including use of risk prediction tools) and management: smoking cessation, blood pressure control, use of statins, diabetes control, proteinuria control
	Enquiring about progression and other risks – enhancing health literacy	Careful assessment of chronic kidney disease progression risk relative to other risks, eg kidney failure risk equation (Tangri et al, 2011)
	Understanding purpose of medicines and avoiding nephrotoxic medicines – enhancing health literacy, discuss treatment burden with clinicians	Careful medicines management including appropriate dose adjustments and minimisation of polypharmacy
	Understanding need for and engaging with activity – enhancing health literacy	Encouraging (and potentially referring for) exercise to improve mobility and strength
	Fluid management, avoiding nephrotoxic medicines, flu vaccination, medication adherence, potentially temporary avoidance of certain medications when sick (although caution in patients who also have heart failure)	Good clinical care to reduce risk of acute kidney injury, eg fluids, sepsis management, avoiding nephrotoxic medications
Enhancing quality of life	Understanding chronic kidney disease – enhancing health literacy through asking about the diagnosis	Careful explanation of the chronic kidney disease diagnosis and its likely causality
	Enquiring about progression and other risks – enhancing health literacy	Careful explanation of progression risk relative to other risks (cardiovascular events, death before end-stage kidney disease). Most people with chronic kidney disease are at low risk of progressing to end-stage kidney disease. Adapt information provided according to the dominant risk
	Understanding purpose of medicines, monitoring and appointments and querying unnecessary visits. Developing strategies and routines to manage treatment burden	Assessing overall treatment burden (consider using a validated measure)
	Enhancing patient activation balanced with burden Consider the importance of peer support, either formal (eg via kidney care networks) or informal (eg social networks)	Supporting self-management without overloading the patient
	Understanding purpose of medicines – enhancing health literacy	Careful medicines management including appropriate dose adjustments and minimisation of polypharmacy
	Understanding need for and engaging with activity – enhancing health literacy	Encouraging (and potentially referring for) exercise to improve mobility and strength
	Inform clinicians about pain. Consider non-pharmacological solutions for pain	Adequately address pain Consider non-pharmacological solutions for pain

attending healthcare appointments, monitoring health, performing self-care and modifying lifestyle behaviours all contribute to this workload. This includes polypharmacy, but goes beyond it to consider issues which can be very burdensome for patients, such as making dietary modifications and attending multiple appointments with different specialists. While by no means unique, such things are very common among the mostly older population of people with chronic kidney disease, who are frequently managing multiple conditions (Fraser et al, 2015, 2016; Tonelli et al, 2018).

Key points

- Patients with chronic kidney disease report shock at the diagnosis, uncertainty about its cause, and worry about the future in terms of progression, treatment, and social and financial burden.
- Helping people to ‘live well’ with a chronic condition should include efforts to reduce future risk of adverse events and to consider how to enhance quality of life now.
- Clinicians can help people with chronic kidney disease to live well by understanding their perspective, communicating clearly and checking understanding, particularly around diagnosis and future risk.
- People with chronic kidney disease commonly suffer from multiple comorbidities and lower quality of life, often experiencing chronic pain, depression, functional limitation, frailty, fatigue and high treatment burden.
- Assessing overall treatment burden is an important component of management.
- Reduced glomerular filtration rate and presence of albuminuria are both associated with increased risk of several poor outcomes including cardiovascular disease, hospitalisation, acute kidney injury and death.
- Interventions to reduce future risk in patients with chronic kidney disease include regular monitoring (particularly albuminuria, estimated glomerular filtration rate and blood pressure), careful assessment of chronic kidney disease progression risk relative to other risks, and careful medicines management.
- Non-pharmacological interventions that may improve mobility, strength and pain should be considered.

Living well with chronic kidney disease

What can clinicians do?

Awareness of the patient perspective and using clear communication

Given the potential for a low level of understanding of kidneys and kidney disease, it is vital that clinicians understand something of the patient perspective described above. This knowledge can be used to inform both what is said and how clinical interactions are approached. It is important to ask ourselves questions such as:

- ‘Is this patient aware of their chronic kidney disease diagnosis?’
- ‘What do they understand about their condition?’
- ‘What is the patient’s main concern?’
- ‘What might they need to know?
- ‘How can I enhance health literacy here?’ (rather than ‘how can I dumb this down so that people understand?’)
- ‘Have I checked back that they understand?’

Having our own uncertainties about chronic kidney disease as a condition risks adding further to patients’ concerns (Kazmi et al, 2018).

Advice for patients

There are important things we can advise patients. These are summarised in Table 3, categorised according to reducing future risk and enhancing quality of life. Some aspects, such as encouraging physical activity, appear in both categories.

Conclusions

Chronic kidney disease is a condition with both specific and general health risks. The population of people with chronic kidney disease tends to have more challenges across a number of domains than their peers. Helping people with the condition to live well includes considering ways of reducing future risk and enhancing quality of life. Patients can, and should, be actively engaged in this in order to enhance their capacity to manage the condition and reduce the burden both of the disease and its treatment.

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Conflicts of interest

The authors declare no conflicts of interest.

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