

Telling the truth:

why disclosure matters in chronic kidney disease



The dynamics of the doctor–patient relationship have evolved over recent decades from a model of benevolent paternalism to a framework centred around shared decision making,¹ for which patient awareness of their diagnoses, and hence disclosure of diagnoses by healthcare professionals, are prerequisites. Some of the complexities and challenges inherent in this paradigm shift are illustrated by the example of chronic kidney disease (CKD), a condition of internationally high prevalence and low awareness.²

In the UK chronic disease management in primary care is incentivised through the Quality and Outcomes Framework (QOF). CKD has been included within the QOF since 2006, but is under-diagnosed in primary care. While CKD stage 3 to 5 prevalence rates are estimated at 6% of the adult population,³ only 4.3% of the population are on CKD registers.⁴ Furthermore, the majority of the QOF-registered population may be unaware of their diagnosis; data from the *Health Survey for England* indicate that only 1.5% of males and 1.3% of females had been informed by their doctors that they have kidney disease.³

REASONS FOR NON-DISCLOSURE AND LOW ASCERTAINMENT

The reasons underlying low ascertainment and non-disclosure in CKD are likely to be complex and inter-related. CKD is still a relatively new priority for primary care with an associated steep learning curve. Some practitioners have concerns over the validity of the diagnosis especially in the older population in whom they view CKD as a normal part of ageing.

The need for a 3-month period of chronicity for formal diagnosis and the relative imprecision of estimates of kidney function obtained using the Modification of Diet in Renal Disease formula⁵ (such that individuals may move in and out of the CKD stage 3 category) continue to present difficulties. Levels of ascertainment may also be negatively influenced by scepticism regarding the merits of rigorous blood pressure control in older people, although there are data showing evidence of benefit.⁶

Once CKD has been identified, there may be uncertainties around the best way to communicate the diagnosis and its implications to patients. Some practitioners will have concerns over the stigmatising and anxiety-provoking impact of a CKD label and the greater consultation time required for a complex explanation of the diagnosis.⁷ There may be other negative aspects of disclosure, such as difficulties with insurance.

These issues are examined in two papers in this month's *BJGP*. McIntyre and colleagues studied the treatment of 1741 patients registered with CKD stage 3 in 32 general practices;⁸ 41% were unaware of their diagnosis. Males, people aged under 75 years, and those with stage 3B disease or albuminuria were more likely to be aware of their diagnosis, as were people with more formal education. This suggests that diagnostic scepticism was an important factor underlying non-disclosure, but also that social class and health literacy inequalities might have been operating.

The qualitative study by Blakeman *et al* of 21 GPs and nurses across 11 practices identified significant anxiety across the two professional groups related to disclosing a diagnosis of CKD and uncertainty over the usefulness of a diagnosis of early CKD in older people, although the embedding of early stage CKD within the wider framework

of vascular care described by some clinicians in this study may mitigate the negative impacts of non-disclosure on patient care.⁹

BENEFITS OF DISCLOSURE

While a reluctance to disclose may be understandable in some circumstances, such practice is divergent from a patient-centred approach to chronic disease management. In the example of CKD, disclosure can provide a platform to discuss lifestyle choices, address vascular risk factors and comorbidities within a model of collaborative self-management, and will avoid missed opportunities to modify disease progression.

CKD is a risk factor for acute kidney injury which is more common than has traditionally been recognised, complicating up to 1 in 5 of acute admissions to hospital and is associated with poor outcome. Patients should be educated on preventative strategies, including adequate hydration and the temporary cessation of medications such as renin-angiotensin blocking agents during periods of acute illness.

A diagnosis of CKD is important for medicines management, both of prescribed drugs, such as opioid analgesics and oral hypoglycaemic agents, and those purchased over the counter, including ibuprofen-containing medications. The medicolegal implications of putting patients on a disease register without their knowledge should also be borne in mind.

A reluctance to inform patients of their diagnosis is not restricted to the setting of CKD. European data indicate that up to 20% of people may be unaware of a prior diagnosis of invasive cancer.¹⁰ Issues of disclosure resonate in the case of dementia, where arguments advanced against informing patients have included uncertainties over the diagnosis, feelings of futility, and the fear of causing distress.¹¹

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While, with the plan for all patients to have access to their primary care records by 2015, the ethical and practical implications of ensuring patients are informed may negate any protective instincts of primary care, it should be emphasised that the evidence base on disclosure is poor. Further research, for example through the Research for Patient Benefit Programme,¹² is required to determine the extent of non-disclosure of chronic disease, the degree of variation in disclosure, the influence of disclosure on patients' levels of anxiety and activation to self-manage, and the impact on behavioural modification and clinical outcomes.

Nevertheless, we should not forget that physicians have a duty, both morally and legally, to disclose truths that patients could reasonably be expected to be told in a sensitive way that they will understand.¹³ Openness, trust, and good communication

are the cornerstones of the doctor-patient relationship.¹⁴ By avoiding difficult conversations and taking a paternalistic approach to disclosure in certain groups we may be failing our most vulnerable patients.

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