



Non-disclosure of chronic kidney disease in primary care and the limits of instrumental rationality in chronic illness self-management



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ABSTRACT

Early detection of long term conditions is predicated on assumptions that lifestyle changes and medications can be used to reduce or manage the risk of condition progression. However, ambiguity remains about the nature and place of diagnostic disclosure to people in newly recognised or asymptomatic ‘pre’ conditions such as early stage chronic kidney disease (CKD). The disclosure of a diagnosis is relevant to instigating strategies which rely on actively engaging patients as self-managers of their own care. Whilst primary care routinely records a diagnosis of early stage CKD, little is known about how patients learn about the fact that they have CKD or how they respond to this. This study aimed to explore patients’ experiences of disclosure of CKD in primary care settings.

A nested qualitative study of participants recruited to a trial of an intervention for CKD patients in Greater Manchester, UK was undertaken. A purposive sample of 26 patients, with a mean age of 72 years (range 59–89, median 71), were interviewed during 2012. Interview transcripts were analysed using constant comparative techniques. Narrative accounts reflected limited or partial disclosure of CKD; often cast in vague terms as “nothing to worry about”. How patients described themselves in terms of participation and their tendencies towards ‘active’ or ‘passive’ involvement in consultations emerged as important components of narratives around disclosure. The findings illuminate the ways in which diagnosis is oriented in a context where it is possible to meet the requirements for remuneration under a pay for performance system of primary care, whilst apparently not disclosing a label or a diagnosis to patients. This challenges the presumptions inherent in wider health policy objectives that are increasingly built on the notion of responsible patients and the ethos of the active support of self-management for pre-conditions.

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1. Introduction

Improving population health through early detection of ‘pre-conditions’ has been linked both to the increased effectiveness of

secondary prevention and the risks of increased surveillance (Howson, 1998). In the United Kingdom (UK), health policy has incentivised surveillance of early stage chronic kidney disease (CKD) in primary care with the detection, recording on a register and monitoring of CKD constituting remunerated Quality and Outcomes Framework (QOF) indicators (eGuidelines.co.uk, 2014). However, little attention has been paid to the ways in which ‘diagnosis,’ or the recording of pre-conditions, is managed in practice, nor the extent to which disclosure might be considered by (and have implications for) patients. In this article, we explore

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disclosure through the results of a qualitative study that was nested within a randomised, controlled trial (RCT) of a self-management intervention for early stage CKD (Blickem et al., 2013). The intervention consisted of information about kidney health and telephone-guided access to community support groups and activities. Given that early stage CKD is currently contested in the biomedical literature, it was felt valuable to explore diagnostic awareness within the context of an intervention designed to provide information about, and open up options for, self-management. The aim of the trial intervention was to contribute to the evidence-base for guided self-management, and fits with current notions of patient empowerment and peer support. Here, we explore patient experiences of the disclosure of a CKD diagnosis.

Enacting long term condition self-management is a growing normative expectation of individuals, with primary care seen as playing a mediating role in its promotion (Dennis et al., 2008). The sharing and disclosure of a diagnosis is likely to be a fundamental pre-condition for transferring management options from health professional to a person living with a long term condition. However, on the face of it, this is a taken for granted aspect of the process. For example, the UK Department of Health (2012) consultation document, “No decision about me, without me” lays out what should happen before or after diagnosis, but ‘diagnosis’ itself appears as a black box process that does not seemingly involve ‘sharing’ or interaction between doctor and patient.

Disclosure of medical information has traditionally been seen as a potential source of conflict in the doctor–patient relationship (Faden et al. 1981) where a diagnosis is not always agreed upon between the two parties (Bugge et al. 2006). In a study of concealment around cancer diagnosis in Italy, Gordon and Paci (1997) identified three sociological themes related to non-disclosure and biomedical ethics underpinning the “social embeddedness” of non-disclosure “practices”: authoritarianism, “a strong ethic of not causing suffering in others” and the “habitus of bioethical practice.” They suggested that “giving reassurance is more important than telling the truth.” In their survey work, they found an association between non-disclosure and increased patient age.

In primary care, lifestyle advice related to reducing blood pressure, drug treatments and monitoring are the recommended CKD management strategies (De Lusignan et al. 2011). According to UK guidelines from the National Institute for Health and Care Excellence (NICE), “People with chronic kidney disease should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals” (NICE National Collaborative Centre for Chronic Conditions, 2008: 6). Models of clinical decision-making have traditionally been characterised as paternalistic or involving either ‘informed choice’ or shared decision-making (Elwyn et al., 1999). Models of patient preferences in decision-making commonly distinguish between ‘active’ and ‘passive’ patients with implied variations according to stage in the life course (Kiesler and Auerbach, 2006). A propensity to involve patients in decision making may differ according to clinicians’ perceptions of when circumstances or conditions might be complex and burdensome for patients. Chronic kidney disease is more common in people with multiple chronic conditions, especially diabetes and other vascular diseases (Fraser et al., 2012). Accordingly, some GPs might be concerned about over burdening patients with diagnoses or treatments, especially in the context of a (pre) condition which is likely to be asymptomatic or even seen as a normal part of the ageing process (Crinson et al., 2010; Moynihan et al., 2013; Taal, 2012).

Trachtenberg et al. (2005) found that trust was a key predictor of the degree to which a US sample of patients were involved in their own care. However, more trusting elderly patients also tended to be

more passive in clinical consultations. In the social science literature, an imperative for trust assumes salience in situations where uncertainty and a level of risk coalesce because of the dependence on the motives, intentions and future action of the other person on whom the individual depends. Thus, ‘trust’ embraces a combination of confidence in competence and a judgement as to whether the ‘trustee’ (e.g. the GP) is judged to be working in the interests of the ‘trustor’ (e.g. the patient) (after Calnan and Sanford, 2004; Gilson, 2003; Mishra, 1996).

Some General Practitioners have expressed reservations as to whether CKD really constitutes a disease and reported difficulty and anxiety in explaining and disclosing the condition to patients (Crinson et al., 2010; Blakeman et al., 2012). Thus, the ability to disclose a diagnosis for remuneration purposes and variations in clinical practice are likely to underlie the communication of diagnostic disclosure. However, little is known about the patient perspective in CKD diagnosis or their views of ‘disclosure’ in this context. The aim of this study was to explore the diagnostic awareness of patients with stage 3 CKD who were recruited to an RCT of a self-management intervention consisting of lifestyle advice and “guided help” around blood pressure control.

2. Screening, disease registers and CKD: incentivising ‘quality’ in UK primary health care provision?

In 2004 the new NHS contract for GP services in the UK incorporated ‘QOF’ as an integral component in an attempt to improve some aspects of care quality via recording of “146 largely evidence-based indicators” (Lester et al., 2006). Important elements of the QOF include the use of templates for the delivery of care and payment for performance in respect of clinical work adhering to these templates. In 2006, CKD indicators and templates were first introduced into the QOF. For 2013/14, the indicators for which practices receive QOF ‘points’ are maintaining a register of adults with CKD Stages 3–5; blood pressure control of patients on the register; the percentage of patients on the register with hypertension and proteinuria who receive recommended treatments; and annual testing of patients on the register for protein:creatinine ratio (eGuidelines.co.uk, 2014).

For the purposes of the findings presented here, it is worth stressing that practices do not receive financial incentives for telling patients that they have been placed on the CKD register. Given the ambiguities and anxieties around CKD management mentioned above, there appears the potential for a disconnect between the self-management aspects of care quality and the ‘evidence-based’ aspects of QOF templates and incentives. On the face of the CKD QOF indicators, it would appear that patients would be more likely to be aware of their CKD diagnosis if they were being medically managed for concomitant hypertension and/or proteinuria. Patients with or without CKD are routinely monitored for blood pressure readings in primary care and other medical settings however, and thus whether patients might link blood pressure monitoring alone to a (potential) CKD diagnosis seems on the face of it unclear.

3. The diagnosis and treatment of CKD in primary care

Three important features underlie the diagnosis and management of CKD in general practice of relevance to a study of patients with CKD stage 3. Firstly, the classification of CKD stages is a relatively new phenomenon (CKD is staged from 1 to 5, although stage 3 is sub-divided into 3a and 3b). Secondly, there has been debate and controversy, both about the staging classification in general and about its utility in the clinical management of elderly people in particular. Thirdly, and following from the preceding section, the

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