“Nothing to worry about”? The meaning of a Chronic Kidney Disease (CKD) diagnosis for patients put on a disease register

We interviewed a group of people who had been recruited to a trial for people with early stage Chronic Kidney Disease (CKD). The wider trial was concerned with finding out whether helping people with early stage CKD to access community groups and activities could reduce blood pressure readings. In the interview study, we set out to explore peoples’ feelings and understanding about being diagnosed with CKD. We were interested in how they had found out that they had CKD and what they thought about the ways in which they had been told. We did not interview health professionals as their views are already known from previous research. There is disagreement in the literature about whether “early stage” CKD actually exists as a clinical condition. This is especially the case in elderly people, as declining kidney functioning is a natural part of the ageing process. However, recommendations exist for clinical management and monitoring of early stage CKD is financially incentivised in the UK and other countries.

During 2012, 26 elderly patients in Greater Manchester, UK were interviewed. Different people were selected in order to get a range of responses (e.g. younger vs. older, employed vs. retired, having other health conditions vs. having CKD alone). There were a total of 440 participants in the main trial. All had been recruited according to a protocol that involved being given explicit information about CKD and having blood pressure readings taken.

Given that all of the people interviewed had been informed that they had CKD, it was surprising that several (7 of 26) were sure that they had never been told about kidney disease in a consultation. Others had been told about CKD but came away from consultations with a view that it was ‘nothing to worry about.’ Reassurance from health workers was a feature of the latter stories which gels with what is known from studies that have been undertaken about GPs’ perspectives of CKD diagnosis. Many (11 of 26) did not believe that there was anything wrong with their kidneys; only one person had been explicitly told that they had been placed on a disease register; and only one person was given health information about CKD outside of the trial procedures. Our findings suggested that patients who are more assertive in consultations, or who recognised CKD and other conditions as lifestyle issues, were more likely to have received fuller information from health professionals—perhaps because they had demanded it.

Ostensibly, the reason that health policy in the UK incentivizes the recording of an early stage CKD diagnosis is so that patients can instigate lifestyle and self-management strategies to reduce the possibility of the disease progressing. However, our study highlights the ways in which a system of ‘diagnosis for payment’ can bypass the patient completely. That is, some clinicians seemingly record a diagnosis in a disease register on the one hand, whilst simultaneously reassuring patients that this is “nothing to worry about,” or in fact “normal” on the other. The apparent disconnect between public health policy and the actions or beliefs of individual doctors creates a potential conundrum for patients with regard to how to interpret medical advice. Because some of the people interviewed voiced high levels of trust in the health service in general, or their own doctor's in particular, they 'trusted' health professionals who told them that CKD was nothing to worry about.

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