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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 (Crimson 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 (Crimson 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

introduction of payments for recording of CKD indicators creates the potential for GPs to be incentivized for undertaking actions (such as blood pressure control in the elderly) that might conflict with usual clinical practice.

A new CKD staging system was first developed by the US National Kidney Foundation in 2002 (Polkinghorne, 2011). Armstrong (2011) outlines how GPs have historically been instrumental in shaping disease classifications, which have the potential to both “structure and contain” care. In this context, one could point to a potential for GPs to (re)shape a classification system (e.g. as derived by expert review of evidence) according to the ‘real world’ management of their own patients in general practice. One important issue in this context is that whilst the CKD classification system is built on progression of renal functioning, the main clinical management focus is on cardiovascular disease (CVD) (hence the need for monitoring and control of blood pressure) (Brady and O’Donoghue, 2010). The laboratory readings used to determine CKD status (eGFR and proteinuria) are independent predictors of CVD and mortality from all causes, as well as of renal disease progression (Matsushita et al., 2010). It is thereby possible to conceive of scenarios where some patients could become confused about the management of CVD in CKD, with lay people potentially more likely to associate kidney ‘problems’ with urinary functioning.

Critics of the CKD staging model have suggested that the available scientific evidence “points to the contrary” and the natural history of CKD is currently unclear (Onuigbo, 2013). Levels of one the laboratory values used in CKD staging (eGFR) decline naturally with age, and thus it has been argued that low results in elderly people are in fact clinically “normal” (O’Connell and Woolfson, 2009). Whilst eGFR is a clinically useful indicator of kidney functioning, the readings are unreliable, especially in those with mildly reduced eGFR (stage 1, 2 and 3a CKD) (O’Callaghan et al., 2011). Thus, there exists the potential for a lack of confidence in the accuracy of eGFR readings in elderly and/or early stage CKD patients. This holds implications for how GPs manage such patients, perhaps especially in the context of multimorbidity and/or polypharmacy. Thus, whilst the evidence-based guidelines advocate tight blood pressure control (including use of ACE inhibitors for patients with proteinuria), in the elderly GPs might face a trade-off between the benefits of blood pressure control and the associated risks of treatment (including an increased risk of falls). The combination of clinical uncertainties surrounding patients with mildly reduced eGFR and questions about the risks versus benefits of tight blood pressure control in the elderly might contribute to an under-recording of CKD in primary care. Thus, the need to use QOF templates in CKD holds the potential for a conflict between this incentivised activity and the treatment or management of elderly patients with mildly impaired kidney functioning. The findings of an English representative population survey put the prevalence rate of CKD (stages 3–5) at 6% (rising to 31% of males and 36% of females aged 75 and over). The results of this survey point to an under-recording of the condition by general practices in the UK and a tendency for patients not to be aware, with less than 2% of men and women with CKD (stages 1–5) reporting having been informed that they had the condition by a doctor (Roderick et al., 2011).

4. Methods

The main aim of the nested qualitative study was to examine patients’ experiences over time of the devolvement and use of the CKD self-management programme, interaction with services and wider social and personal resources and networks. The population for the qualitative study consisted of a purposive sample of patients recruited to the BRIGHT trial who all had a diagnosis of CKD Stage 3.

The analysis presented in this article is based solely on baseline interviews, which were broadly concerned with interactions with health workers, management of health conditions in general and social networks in peer support. Whilst short follow-up interviews were undertaken, these did not provide any further insights into perceptions of diagnostic status or experiences of clinical communication about CKD. The focus here is on accounts of diagnostic disclosure. Some other interviewees in the intervention arm of the trial were recruited for a separate process evaluation specifically of the telephone guidance around community support. These findings are reported elsewhere (Blickem et al., 2014).

The overall approach adopted in the nested qualitative study is best described as a comparative case study approach. The methods of sampling and data collection were based on elements of grounded theory (Glaser and Strauss, 1967)—because little is known about patients’ views of CKD disclosure. However, biographical or narrative approaches (Riessman, 1993) characterised the way that interviews were undertaken and constantly compared with one another. The aim of the sampling strategy was to achieve maximum variation in narratives around CKD disclosure. Accordingly, narratives were analysed as data were collected, in constant comparative manner, in order to target further sub-groups of patients to be interviewed. Differences in interviewees’ awareness of having CKD was used as a primary framework for the analysis.

The study received NHS ethics committee and local R&D approvals. At the time of recruitment to the main trial, participants gave consent to be contacted by a researcher to ask if they would also undertake a face-to-face interview. Of 30 people identified as potential recruits to the study, 26 (86.7%) agreed to take part. One could not be contacted and three refused for various reasons. Interviewees were given a £10 shopping voucher at the end of the interview, which typically lasted for around an hour. All interviews were conducted by the first author and transcribed by a professional transcription agency.

The first five interviews were used to refine the line of questioning and allowed the interviewer to ‘test the water’ in relation to the delicate handling of interviews about a condition that some interviewees believed they had not been told about, or did not believe that they had. Efforts were made to achieve an equal number of interviewees in the control and intervention arms of the trial and a reasonable gender mix. Interviewees in the intervention arm were asked about the information they had been given about CKD as part of the BRIGHT trial. Members of the control group did not receive this information and could not be questioned about it. They were also not asked about written information in CKD due to the potential risk of such discussions leading to ‘contamination’ of the control arm of the trial. The first eleven transcripts were each analysed by both the first author and one of the other authors and theoretical notes and memos were made using the comment feature in word processing software. The focus was on the overall narrative in each transcript and the exact words reported as being used by health workers in relation to CKD. Later, we compared accounts according to degree of diagnostic disclosure and examined the circumstances and attributes that appeared to be associated (in a conceptual sense) with disclosure/non-disclosure. Finally, we compared selected and grounded themes from accounts in a grid (akin to a 2×2 table in statistical research) setting disclosure status against whether interviewees reported being ‘active’ or ‘passive’ in consultations with primary health care workers. This framework represented a conceptual ‘best fit’ to describe the findings, as commonly used in grounded theory approaches to qualitative data analysis. Previous attempts to explain variations in reported disclosure by other means (e.g. according to length of time since being placed on the register, presence or absence of comorbidities, attitudes or

satisfaction towards GPs on other matters and with gender or other demographic features) were unsuccessful.

5. Results

5.1. Overview

Twenty-six participants in the BRIGHT trial were recruited to the nested qualitative study, with equal numbers taken from the intervention (8 women, 5 men) and control (4 men, 9 women) arms. The interviewees were elderly, with a mean age of 72 years (range 59–89, median 71). These figures were commensurate with those of the 440 total participants to the BRIGHT trial from which the sample of interviewees was drawn (mean 72 years, range 40–90, median 72). The interviews revealed that just over half (15/26) had received a diagnosis of CKD prior to their involvement in the trial, although the specifics of the information disclosed varied considerably (see below). Four people only learnt about the status of their kidneys as a result of being enrolled into the trial and the remaining seven perceived that they had still not been informed that there was anything wrong with their kidneys even in the context of recruitment to the trial.

5.2. Disclosure, partial disclosure and non-disclosure

Analysis of the accounts revealed that most patients' CKD stories fell into two main types: those who felt that they did not have anything wrong with their kidneys and those who recognised the issue but had been reassured that this was nothing for them to worry about (Table 1). It should be stressed that even some who had apparently received a 'full' disclosure of CKD were still adamant that there was nothing wrong with their kidneys. Those who had been told something about CKD by health workers were compared on a continuum and 11 (of 19 who were disclosed information) appeared to have received a partial disclosure whereas 8 described a fuller disclosure. "Full" disclosure involved patients being explicitly told that they had "Chronic Kidney Disease" (cases 10, 24, 25, 26); that their kidneys were "failing" (case 6); or, they were prescribed drugs within a consultation about impaired kidney functioning (case 16). Two further respondents who were characterised as having a "full" disclosure were informed of impaired kidney functioning as a result of scans for other health problems in secondary care (cases 11 and 22).

In some cases, patients were told that they—variously—"might" (case 17) have a "slight" (case 11) case of "mildly impaired" kidneys (case 3); "just on the borderline" (case 4) but that it could be normal for their age (cases 8 and 11, for example). In other cases, people reported having been told that their kidney functioning was

being monitored, usually because of prescription drugs they were taking, but they nevertheless maintained that there was nothing wrong. The alternative narrative here, as in cases 19 and 23, was that there had been only one irregular result in a long series of tests which constituted a "blip" or "just a one off" since which everything had been fine (case 19).

Interviewees in the intervention arm were routinely asked what information people should be given about CKD, and many stated that doctors should disclose medical information to patients. As case 20 put it, "I like the truth, come straight out with it, I can deal with it." However, when asked, many interviewees, although disproportionately more elderly women, reported that they would not even consider asking their GP any questions. Sometimes this was because of shock but in other accounts it appeared to reflect a view that doctor knows best. Another commonly reported experience was that people had been told (or not told) different things by different GPs:

... but I was so shocked anyway, and my, my daughter made an appointment to see the doctor with me 'cos she said, "Why wasn't I informed?" And he ... of course the doctor said, "Well, I naturally thought another doctor had told you." You see different doctors and ... I suppose they think the previous doctor's told you. (Case 22: 3: 12–15)

Some of the men interviewed reported being active in engagements with primary care practitioners. It was noted in case 9, a female retired health worker, that because information about CKD had been related by the practice nurse, the interviewee construed this as meaning that the condition was not serious. For case 4, the asymptomatic nature of CKD, as compared to the symptoms of other conditions, meant that it was not something that she was bothered about, neither in terms of information and advice nor active management:

Respondent: She said "Don't worry it's on the borderline [inaudible 05:20]." Like that, you know, so I don't know really.

Interviewer: Have you ever been given any advice from your GP or the, the practice nurse at the GP, about diet or exercise?...

Respondent: Er, well I don't know. I'm more concerned really about, erm, about the problems I have in myself as I know about. I mean I know you can have problems that you don't know about, you know, like diabetes and different things like kidneys, me kidneys and that. And blood pressure, you know a lot of people are walking about with it now, you know. But I wonder more about the, you know, not actually worry, but you know.

Interviewer: ... I think when I came before [the interviewer also visited this and some other interviewees to collect baseline questionnaire data for the main trial] you mentioned that you had a few, er, health problems don't you?

Respondent: Yes.

Interviewer: What are the main ones that cause you problems on a day to day kind of ... ?

Respondent: Pain, me, erm, pain, me legs and me back and me neck, yeah. (Case 4, 4–5: 14–1)

For people with other medical conditions, the prioritisation of an asymptomatic condition like CKD stage 3 was unlikely given the possibly troublesome nature of symptoms of other conditions (e.g. arthritis, diabetes, strokes or heart attacks) and the objective of many who sought to limit their intake of prescribed drugs.

Table 1
Overview of patient narratives around CKD diagnosis and disclosure (n = 24).

Main theme	Members
I don't have a problem with my kidneys	Interviewees 2, 7, 12, 13, 14, 15, 18, 19, 21, 23, 25
It's nothing serious	"She just said it was impaired kidneys" (#1); "Under par" (#3); Nothing to worry about (#4, #10, #20); Nothing explained, just a 'casual remark' about kidneys (#5, #22); "It's only old age kidney problems", "My kidneys are the least of my problems" (#8); "Just a couple of notches lower than what they should have been" (#9); "It's probably your age" (#11); "I was just told that I might have it" (#17); "Something that they are just keeping an eye on" (#24); "Nothing serious" (#26)

A number of accounts suggested that patients were comfortable with a status quo where doctors led communicative encounters and patients remained passive. Some patients appeared content to leave health related matters to medical professionals rather than bother about things too much themselves. Others were reassured that in spite of their identification as being at “increased risk,” there was in fact nothing wrong with them and they had nothing to worry about. However, in the reported absence of medical explanations for their membership of a diagnostic category, some patients were left to formulate their own explanations. These commonly centred on the potential of drug treatments themselves to adversely impact on kidney function. In one particular case (5), a woman with diabetes attributed a failure to control the condition with the appearance of a CKD diagnosis, which was linked to prescription drugs used in the treatment of arthritis:

Interviewer: So you've always ... been having these tests over the years, but it was only two months ago that you were told that there was something wrong?

Respondent: Yes. Because they couldn't control my diabetes. And he just ... it was just a casual remark, it wasn't really much, he just said, “Er, your kidneys might be leaking.” No explanation, no nothing.... Which is so unusual for my doctor because he's a lovely man. And I just ... and I didn't even ask him anything about it or ... I just come away, I just didn't ... it just didn't register.

Interviewer: Is that because you were shocked or ...

Respondent: I think so.

Interviewer: ... you didn't think it was important, or ... ?

Respondent: I think it was because I was shocked.

Interviewer: Okay....

Respondent: All I know is, um, because I have arthritis, I used to have regular blood tests because they said the tablets could affect the kidneys. (Case 5, 3: 6–23)

On occasion, patients had seemingly been told about CKD in simplistic, informal or ‘lay’ terminology (e.g. that (one of) their kidney/s “were/was leaking” (cases 4, 5 (above) and 20) or that they had a “lazy kidney” (e.g. case 13)). It is assumed that this was done to make things easier for patients to understand, but the effect seemed to rather be the opposite and those patients who were bothered about it to any degree were seemingly left to construct their own fuller explanation. On one of the few occasions when a patient had been told their results in the form of specific figures, the more detailed information was seemingly no help in translating the disclosure into a form that would have been of use in self-management terms:

“And, erm one doctor gave me my results, and I can remember being told last time, ‘You were down a bit, it was 57,’ which meant nothing to me, I didn't take that on board really, I didn't take any notice of it, and, ‘But you're fine,’ and no more.” (Case 23: 2: 24–27)

Several patients were insistent that they had nothing wrong with their kidneys. For case 14, the test result showed that “everything was fine.” Case 15 was sure that her GP had never used the word “kidneys” in a consultation. One woman (case 18) was similarly adamant that she had never been told anything about her kidneys, although during the course of the interview she did state that her GP had told her to “drink more” on several occasions. This

could suggest that case 18 did indeed have kidney problems, although her GP had issued health advice without an accompanying diagnostic label. However, case 18 reportedly ignored this advice and carried on drinking the same amount of fluids that she has always done, “Because I'm not poorly.” At the end of the interview, she reflected:

“You know, if I was to wake up one morning and think, ‘Oh, there's something the matter with my waterworks,’ then I would go to the doctor. But at this moment in time I haven't got anything wrong. And I really don't know what symptoms to look out for if I did have kidney disease.” (Case 18: 39: 13–16)

5.3. Nondisclosure, trust and the potential for diagnostic burden

Qualitative studies of GPs' attitudes towards CKD have highlighted the capacity of the diagnosis to frighten patients (Crisson et al., 2010), making reassurance a necessary part of diagnostic disclosure (Blakeman et al., 2012). In the preceding section, we discovered how apparent attempts at “reassurance” played out, e.g. via assertions by health workers that CKD stage 3 is “normal” or “nothing to worry about.” Whereas some patients challenged what they perceived to be vague or partial information giving, others articulated trust or confidence in their doctors, or in the health system, which led them to perceive that CKD was indeed nothing to worry about. These themes are reflected in the following interview extract:

Interviewer: When you found out that you might have something wrong with your kidneys, was this a shock to you, or was it something you were concerned about?

Respondent: No, I wasn't unduly concerned because I was, an ... I have full confidence in the health services ...

Interviewer: Right.

Respondent: ... and I felt that if there was something serious they would have told me.

Interviewer: Okay. Have you ... since all of this has come to light have you been back to your GP to try and find out more or have you been anywhere else for any ... ?

Respondent: I spoke to the nurse about it.

Interviewer: Okay, and what did she tell you?

Respondent: She says well, it's not a ... something serious, you've got a lazy kidney. One's not just up to the standard of the other one. (Case 13: 2-3: 25–8)

Case 10, was among those who had sought further information from their practice about CKD following the recruitment procedures for the trial. Having learned of the diagnosis from a nurse he reported initially being “worried sick,” and prepared to “go in and play hell” with his GP. However, following a consultation with his GP, he was “reassured” that his kidney function was in fact “normal” and the apparent concealment of monitoring of his kidney functioning (over a period of ten years) was used to bolster the view that the condition was nothing serious. Here, implicit trust was being articulated whereby if his GP had believed CKD stage 3 was serious, or something to worry about, then he would have been informed earlier. However, such confidence and trust in GPs was only mentioned by a small number of respondents and seemed particular to those with longstanding relationships with their doctor:

“Over the years, I've got to know them and they've got to know me and I ... I just trust them, I think, if anything, er, could be said that would help me, they would tell me, mm.” (case 24: 20: 16–19).

Following from the above, we suggest that an apparent trust to “tell me” has been extended to a trust related to not being told about information that is seen as unimportant. Some of those in the trial intervention arm were also prompted by a cartoon in the CKD handbook and stressed that GPs needed to consider whether individual patients would be able to cope with a “chronic” label that had the capacity to provoke anxiety or fear of impending death. However, it was not at all clear from respondents' accounts how GPs would be able to discern which patients would be able to handle this potentially disturbing information or not. The potential capacity of a “fuller” disclosure to frighten individuals, and the role of reassurance in diagnostic communication around CKD is best exemplified in case 24 (Box 1), who was the only interviewee who reported explicitly being told that they had been placed on the “chronic kidney disease register.”

Box 1

Description of a fuller disclosure: fear and reassurance.

Interviewer: Right, okay. So you started at a new, erm, surgery and it was the, er, the practice nurse who told you. Do you remember exactly what she said to you?

Respondent: Er, just what I've said to you, when ... when I went the following week for the results of all, you know, the urine sample, the blood test, etc., etc., she said, er, one of the tests showed that my kidneys weren't working at full capacity and my doctor had put me on the kidney disease register so that I would be kept an eye on.

Interviewer: Right. Right, okay, erm, and how did you feel being given that, er, news?

Respondent: Well, when they said, “kidney disease register,” they frightened me to death, to be honest! Erm, but when it was explained to me what it is, I was reassured then.

Interviewer: Right, okay. How did they, erm, reassure you?

Respondent: They told me that it didn't mean I had a chronic illness and I was going to die in three months, etc., erm, and they were just going to monitor me at regular intervals, which they have done.

... [Later, during the same interview] ...

Interviewer: And have they told you if your result has stayed the same, or gone up, or down?

Respondent: It's never gone ... it's never gone worse.

Interviewer: Right, okay.

Respondent: Erm, a month ago, they were quite pleased with me.

Interviewer: Right.

Respondent: Yeah.

Interviewer: And did ... what did ... did they say that your result had improved, or ... ?

Respondent: Yeah, they said my kidney function had improved, yeah.

Interviewer: Right, okay. So is it still ... are your kidneys still not working properly then, or have they now gone back to normal?

Respondent: No, they're still not working properly, but I feel perfectly alright, I'm not aware that ... until they told me, I wasn't aware I had a problem.

Interviewer: And were you given the opportunity to ask any questions, or did they explain things in a bit more detail about what the implications of what ... of what this might ... might be for you?

Respondent: No. No, they didn't elaborate on it.

Interviewer: Would you have liked them to?

Respondent: I don't think so.

Interviewer: Okay.

Respondent: I don't think so, I think, I don't think so, I think, maybe I'd have worried about it if I'd known a bit more. I can tuck it in the back of my mind now and just get on with my life and, well, if it becomes a bigger problem in the future, then, obviously, I will want to know.

(Case 24: 2-4, 24-15)

5.4. Disclosure and active communication in medical encounters

The narratives underlined diagnostic disclosure as a temporal process. In some respects this is not surprising given the need for continual monitoring at periodic intervals. However, an additional influence appeared to be the extent to which patients considered themselves as ‘active’ communicators in GP and practice nurse consultations. This seemed to be a feature of 23 of the 26 accounts. Although the general tendency was towards varying degrees of non-disclosure, most of those who tended to identify themselves towards a predominantly passive or receptive stance reported having had the diagnosis undisclosed, whereas some of those who identified themselves with a more active engagement style in consultations had reportedly received full disclosure.

Case 16, was one patient who had received full disclosure, but he was unusual in only being aged in his fifties at the time of diagnosis (and disclosure). He was also unique in that he had volunteered for a community health screening programme, and this might explain why he accepted CKD as a lifestyle and prevention issue. This account was one of two that did not fit the framework represented in Table 1. He described being very active in interactions with his doctor, criticised an approach focused on the use of medications and had successfully negotiated access to a health trainer as an alternative to prescription drugs. Case 26, a 66 year old man, still young compared with many other respondents, also appeared as an active participant in medical encounters, although in his case it was less clear whether disclosure was rather associated with good clinical practice (see also below). Finally, Case 25 was an active communicator aged 69 years who had received full disclosure, although he had fiercely resisted the diagnosis, mainly because he sought to stop taking blood pressure medication and he felt that a designation of CKD would limit that possibility.

In those aligned to accounts of more active communication where the diagnosis had not been revealed it appeared that people had either been told that there was nothing wrong with their kidneys (cases 2, 7, 18, 19) or that it was nothing to worry about (cases 4, 8, 9, 11, 20) (see also Table 1). These interviewees were older and the majority had a history of numerous conditions/symptoms or adverse health events (cases 2, 4, 7, 8, 9, 11, 18, 20).

Only one interviewee appeared as a passive communicator who had a diagnosis revealed. However, her account represented a deviant case (6) in that she was the only person who had been told that she was in immediate danger of renal failure. The diagnosis was linked to arthritis medication which was stopped and changed to alternative drugs. She was also atypical compared to the rest of the sample in reporting symptoms perceived to be directly related to kidney functioning in the form of increased urinary frequency. Following the CKD diagnosis and change in her prescription drugs, her kidney functioning was now described as “liveable with ... from what I can gather.” This account was one of two that did not fit the framework represented in Table 1.

Eight narratives suggested a greater degree of passivity in terms of communication. These were from people who reported that they had not had diagnoses revealed to them. Typically, these interviewees reported that they did not ask any questions of their GPs during consultations – either out of fear, respect, forgetfulness or a shortage of time – but simply accepted whatever they were told. An equal number felt that there was nothing wrong with their kidneys (cases 12, 13, 14, 23) or that the condition was not serious (cases 1, 3, 5, 17) (see Table 1). Case 23 was unusual compared with the others in this group in that her younger age (64), former professional occupation (teacher) and adherence to a lifestyle/prevention model of health, suggested that she might rather have been an active medical consumer who engaged with her GP during consultations. However, when it came to interactions with her GP,

she reported never asking any questions and her account reflected a paternalistic view that doctor knows best.

5.5. *The blocking of nascent opportunities for communication?*

One woman (case 15) was absolutely adamant that there was nothing wrong with her kidneys and denied that her GP had ever used the word “kidneys” in a consultation. However, she was caring full time for her disabled husband, who “never leaves that seat” (in front of the television). The only time she left the house was to visit the supermarket once a week as she reported that she was fearful of leaving of him. Although she was diagnosed with type II diabetes 12 years ago, and was being treated for a thyroid problem, it appeared as though her medical concerns were focused on her husband, and in this context, putative engagement with an asymptomatic CKD stage 3 diagnosis appeared limited. The asymptomatic nature of CKD meant that it was unlikely to receive priority given more pressing concerns.

Case 24, was unusual in having received a full disclosure (see [Box 1](#)) and this was linked to the perception that her GP was of the “good,” “old fashioned” kind (despite being young in age). This interviewee was the only one explicitly informed that she had been put on the “chronic kidney disease register.” From her account, it was unclear whether she could be characterised as having either an active or passive role in consultations, but the overwhelming theme rather concerned a perceived lack of meaning of a CKD diagnosis. Thus, whilst she received “reassurance” from the practice nurse that this is something “that they are just keeping an eye on,” she had never been told the detail of her test results and her GP had himself never discussed CKD with her. She expected more information about the meaning and consequences of the diagnosis which she did not feel were adequately explained. In common with many others, however, and in spite of disclosure, she reported that she had no symptoms related to her kidneys and thus did not feel that she had a disease. She expressed the view that disclosure needs to be done in a way that does not include the words “chronic” or “disease” which she found alarming. Thus, in this case, it was not possible to ascertain whether the interviewee was ‘active’ in consultations or not given the material gleaned during the interview.

In the narratives of cases 21 (diagnosis concealed) and 22 (diagnosis revealed, in part) the main issue in the account of consultations related to CKD non-disclosure was the problem of always seeing a different GP when visiting the practice. In case 22 (a 78 year old woman) partial disclosure was seemingly made by accident by a different GP to her own doctor, who had told her, “Well you do know that your kidneys are only working 50%, don't you?” This news came as a shock. The doctor told her that he assumed that somebody else had given her the diagnosis as it had been on her records for the preceding 5 years. In a direct opposite manner, case 21, who reported always seeing a different doctor when he visited his GP surgery, reported being explicitly told by one GP that his kidneys were “perfectly alright.” After the tape recorder had been switched off, the interviewee suggested that he would have been told more had he still been seeing his former GP who was now retired. Thus, systems issues could seemingly work for diagnostic disclosure, or against it, depending on the individual GP seen at each appointment.

6. Discussion

This study of patient narratives in CKD diagnosis has illustrated how disclosure practices can play out and are interpreted by (and have implications for) patients. The findings of this study suggest limited or partial disclosure of CKD diagnoses, which resonates with health professional accounts of CKD disclosure and with

previous sociological observations about the diagnostic process (see e.g. [Blaxter, 1978](#); [Brown, 1995](#); [Jutel and Nettleton, 2011](#)). A key influence on the subjective awareness of having CKD related to the extent to which patients reported being involved, or participating in, discursive encounters with GPs and practice nurses. These findings cast some uncertainty in relation to presumptions about “shared decision-making” and delivery of lifestyle advice, which are supposedly linked to the goal of monitoring early stage CKD in an attempt to limit the future costs and consequences. The blocking of possibilities for the potential enactment of patient self-reflection and the initiation of self-management activities, e.g. self-monitoring or seeking further information, sits at odds with the rationale for screening and monitoring of CKD in the first place. This tension most importantly points to an apparent disconnect between clinical activities undertaken for the purposes of “points” or remuneration and the communication of diagnostic information to patients.

Patient strategies and self-management practices are predicated to a large extent on open disclosure and discussion as to the implications of a diagnosis. Two interviewees were found not to fit with the analytical framework: one much younger than other participants and one who had previously reported a history of renal symptoms. Thus, our results seem to refer mainly to elderly patients with asymptomatic kidney disease. One limitation was that data constituted historical accounts of clinical encounters, rather than observation of actual encounters. These limitations point to the possibilities of further research, perhaps in the form of surveys of patient sub-groups and recording or observation of clinical encounters.

Although patients seemed to need and value reassurance, in the face of partial or non-disclosure it could result in an over-trivialisation of the condition or suspicion or rejection of medical information related to other conditions (data not shown). The accounts of this elderly sample of patients to a large extent reflected traditional expectations of encounters leaning more to a paternalistic acceptance of what it is appropriate to expect in encounters between health professionals and patients. However, this was less evident in the narrative accounts of younger people and in people with professional or technical employment histories, including health care.

Those who subsequently became aware of surveillance and recording of kidney function in primary care reacted with surprise, fear and disbelief at learning that they had a “disease” in the absence of a history of symptoms. The problem it seems with defaulting to a ‘doctor knows best’ approach is that when patients were presented with partial information, or facts which were perceived to have been hidden from them for some time, they were free to assume that this was in their best interests. For some, tensions, conundrums and paradoxes were then thrown up about their health, the aetiology and symptoms of other health conditions and their relationship with their GP.

Health professionals form a part of the self-management life-world of patients as part of a recursive relationship between the clinic and condition management in everyday domestic settings, with inputs from a wide range of relationships within personal communities ([Rogers et al., 2007](#)). From a clinical perspective non-disclosure may offer benefits in simultaneously removing the need for both illness and treatment burden. However, for patients non-disclosure brings to the fore the potential denial of an equality of knowing what is being recorded about them and what health professionals know about their kidney functioning. Non-disclosure may also remove an added rationale for taking self-management action (e.g. through self-monitoring of blood pressure or adherence to medication). In this respect the findings of this study also reflect those of medical non-disclosure practices in other

conditions: a non-negotiated paternalism in pursuit of a desire not to cause suffering within the cultural practices of biomedicine (after Gordon and Paci, 1997).

The example of early stage CKD has afforded an opportunity to assess the impact on patients of emerging or contested or 'pre' disease categories. The variation in reported disclosure practices, as described by patients, would seem to suggest that being given a diagnosis is in some ways a matter of fate or luck, much as disease and illnesses tend to be in lay epidemiological terms (Davison et al., 1991). However, even though variations in physicians' practice seemed pre-eminent across patients' accounts, there were also differences in patients' awareness of their own diagnostic status according to the degree to which they had engaged with clinicians over matters of screening, testing and diagnosis. Screening for conditions has increasingly blurred the boundaries between disease and risk of disease (Aronowitz, 2009), e.g. as in pre-diabetes.

A longitudinal qualitative study of review consultations for patients with long-term conditions, found that the QOF has reinforced a "biomedical agenda" where patients' management needs can be denigrated in favour of clinical surveillance (Chew-Graham et al., 2013). As with historical studies of primary care consultations, the patient agenda can be ignored (e.g. Stevenson et al., 2000). Thus, the QOF has the capacity to "socialize patients into becoming passive subjects of 'surveillance'" (Chew-Graham et al., 2013). These issues were clearly evident in accounts of CKD disclosure in primary care (itself a QOF performance indicator) which also point to issues of trust and 'confidence' in diagnostic disclosure and non-disclosure. Identifying and recording a diagnosis of CKD relates to a 'logic' of population based medicine (extending healthy lives of vulnerable population groups) (see also McDonald et al., 2013). However, the latter was not related to the dimensions of organisational activity operating in primary care about CKD. At the time of the study recording was oriented to the pay for performance criteria in primary care which did not interface with the arrangements or ethos for public health. Whilst a public health focus is a logical focus of CKD monitoring, the 'pay for performance' arrangements appear to take precedence.

The findings of this qualitative study of patients' perceptions of CKD highlight challenges for the enactment of public health policies and strategies in relation to patient empowerment and shared decision-making in long-term condition management. To some extent the findings here resonate with a long standing literature about doctor-patient communication concerning medications in primary care, where minimal opportunities for shared decision-making are not uncommon and are associated with a traditional paternalistic model (Stevenson et al., 2000; Barry et al., 2001). However, the more recent public policy of 'pay for performance' in General Practice brings with it new systems and incentives for monitoring and recording of symptoms and health outcomes which are principally directed at—and for—the benefit of the smooth and successful operation of primary care organisations. In particular this sets up new imperatives which have the capacity to increase tension inside a framework that pre-supposes that patients can—through contact with primary health care professionals—make the lifestyle and other changes necessary to improve their individual health. These tensions emanate from the increased use of electronic patient record systems, templates for medical consultations, payment for undertaking tasks or reaching targets and increased use of clinical guidelines for management or treatment. The findings of this study concerning CKD in primary care lead us to question whether the kinds of structural changes referred to have enhanced or rather limited the opportunities for more involvement of patients in their own care. The 'competing logics' of population-based medicine and medical professionalism already present challenges for medical practice in primary care (McDonald et al.,

2013). Early stage CKD seems to encapsulate such competing challenges and begs questions about whether instrumental 'evidence-based' solutions constructed at the population level are compatible with the individual enactment of self-management of risks of possible future ill health burdens.

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