

Background

Pruritus, or itch, is common in chronic kidney disease (CKD); in the 2012-2015 Dialysis Outcomes and Practice Patterns Study (DOPPS), 18% of people on haemodialysis were very much or extremely bothered by itch, which had a substantial negative impact on their work and social life. Although treatment is available, itch remains unreported in 17% and untreated in 20% of severely affected patients. We undertook a qualitative study to explore the reasons for this underreporting and undertreatment.

Methods

We conducted individual, semi-structured interviews with 25 itchy patients with CKD (any stage) and ten nephrologists, and organised three focus group interviews with twelve renal nurses from three renal units in the UK. Interviews were audio-recorded, transcribed verbatim and coded in duplicate independently by two researchers. We analysed coded data thematically using Framework Analysis.

Results

Patients

Despite the effect of itch on patients' sleep and social and emotional wellbeing, and their attempts to self-manage, many had never discussed itch with a renal clinician. Most patients had never been asked about itch and had to raise the issue themselves; only a few had been routinely asked: "*it would be a good idea if the consultants just listed that as one of the questions they ask*" (female, 68 years, dialysis). Reasons for patients not reporting itch were: not being aware of the relationship between CKD and itch; embarrassment of being thought unclean; and perceived dismissive attitudes from clinicians towards itch: "*He said well don't worry about it and that was his answer*" (female, 89 years, dialysis). Some accepted itch as a consequence of their kidney disease, often after having tried several treatments for it without effect: "*If the kidney failure is causing the itching there's nothing I can do about it, there's nothing they can do about it; they can give me something to [...] ease the itching; which it hasn't helped so far, so I've just got to get on with it*" (female, 77 years, pre-dialysis). Also, itch severity varied over time and did not always coincide with intermittent clinic visits; limited consultation time further led to patients prioritising other health issues for discussion with the nephrologist: "*In the early days, I mentioned it [itch], but I usually have so much to talk about that it isn't something that has come up in recent times*" (female, 68 years, dialysis).

Clinicians

Most clinicians considered itch of secondary importance within the management of CKD and expected patients to volunteer the symptom; only a few, mainly nurses, would routinely ask about itch: "*I'm more interested in weight loss, appetite, nausea, vomiting, and other kinds of uraemic symptoms*" (male, consultant, 14 years clinical experience). Many clinicians erroneously believed that high phosphate levels were an important cause of itch. There was a wide variety in diagnostic and management strategies, and a lack of knowledge of and dissatisfaction with available treatments: "*I have to say, I find it not an easy symptom to treat [...] Maybe I'm missing out somewhere [...] maybe I need to be a bit more up to date [...] I've very rarely used things like gabapentin*" (male, consultant, 23 years clinical experience); "*Antihistamines [...] I don't find that they're necessarily useful*" (female, consultant, 12 years clinical experience).

Conclusions

Underreporting of itch is related to patients' not being aware of the link with kidney disease, embarrassment, and timing and duration of clinic visits. Clinicians assign low priority to itch and often fail to ask about it; their management strategies vary widely and are not necessarily evidence-based. Our findings warrant the development of clinical practice guidelines to improve the reporting and management of CKD-associated pruritus.