Original Article

Reasons for Underreporting of Uremic Pruritus in People With Chronic Kidney Disease: A Qualitative Study

Giovanni Aresi, PhD, Hugh C. Rayner, MD, Lamiece Hassan, PhD, James O. Burton, MD, Sandip Mitra, Caroline Sanders, PhD, and Sabine N. van der Veer, PhD

Centre for Health Informatics, Division of Informatics, Imaging and Data Sciences (G.A., L.H., S.N.v.d.V.), Faculty of Biology, Medicine and Health, Manchester Academic Health Science Centre, The University of Manchester, Manchester; University Hospitals Birmingham NHS Foundation Trust (H.C.R.), Birmingham; University Hospitals of Leicester NHS Trust (J.O.B.), Leicester; Manchester Academy of Health Sciences Centre (S.M.), Manchester University Foundation Hospitals, Manchester; NIHR Devices for Dignity Med Tech Co-operative (S.M.), Sheffield; National Institute for Health Research School for Primary Care Research (C.S.), The University of Manchester, Manchester; and National Institute for Health Research Greater Manchester Patient Safety Translational Research Centre (C.S.), The University of Manchester, Manchester, UK

Abstract

Context. Uremic pruritus, or itch, is common in people with chronic kidney disease (CKD) and has a negative impact on their lives and well-being. However, for reasons currently unknown, itch often remains unreported and therefore untreated.

Objectives. To explore reasons for underreporting of itch to provide pointers for improving itch reporting and management in people with CKD.

Methods. We interviewed adult patients with CKD who self-reported experiencing itching in the last three years ($n = 25$), nephrologists ($n = 10$), and nurses ($n = 12$) from three kidney services in the U.K. Topic guides were informed by previous studies and a theoretical model of self-regulation. We conducted a thematic analysis of verbatim transcripts using framework analysis.

Results. We identified the following three main themes reflecting factors that may influence whether itch is reported: knowledge on causes and treatment of itch (lack of awareness of the relationship between itch and CKD, and lack of knowledge of treatment options); attitudes toward importance of itch as a health issue (patients' and clinicians' attitudes); and prompts for itch assessment during consultations (routine practice, itch as a marker, and itch severity).

Conclusion. Underreporting of itch is related to patients being unaware of its causes, accepting it as something to live with, prioritizing other health issues, and the length and timing of consultations. Health care professionals' assessment and management of itch vary widely and are not necessarily evidence-based. Better patient information, development of clinical practice guidelines, and incorporation of routine symptom assessments into care may improve itch reporting and management in people with CKD. J Pain Symptom Manage 2019;58:578–586.

Key Words

Chronic kidney disease, uremic pruritus, patient-generated health data, symptom management, qualitative research

Address correspondence to: Sabine N. van der Veer, PhD, Centre for Health Informatics, University of Manchester, Vaughan House, Portsmouth Street, Manchester, M13 9GB UK. E-mail: sabine.vanderveer@manchester.ac.uk

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Introduction

Symptom burden is high in people with chronic kidney disease (CKD).[1,2] This negatively affects patients' quality of life, and increases the risk of depression and treatment non-adherence.[3–5] Improving symptom management is a research priority for CKD patients,[6] and clinical practice guidelines recommend it as a key element of CKD care.[7–9] But despite their prevalence, impact and importance, CKD symptoms often remain unrecognized and untreated.[10–12]

Uremic pruritus, or itch, is a common, yet often overlooked CKD symptom, with estimated prevalence ranging from 25%[13] to 44%.[14] Although the underlying mechanisms that cause itch in people with CKD remain poorly understood,[15] there are several recommended nonpharmacologic and pharmacologic treatments available, such as gentle soaps and moisturizers, topical ointments and gabapentin.[16–18] Nonetheless, 20% of severely affected patients in a large cohort study—the Dialysis Outcomes and Practice Patterns Study—were not treated for itch,[12] mirroring low treatment rates found in other studies.[11,19] Untreated itch is associated with disturbed sleep, depression, higher resource use, and lower general health and quality of life in a dose-response manner.[13,14,20–22]

Health care professionals tend to underestimate the prevalence of itch.[12,23,24] One explanation may be that patients do not always report itch: 17% of severely affected patients in the Dialysis Outcomes and Practice Patterns Study said they had never discussed their itch with a health care professional.[12] However, reasons for underreporting of itch in CKD are unknown. It is also unclear if and how patients' reporting behaviors are influenced by how health care professionals view, discuss, and manage itch. Therefore, we conducted a qualitative study that combined patient and health care professional interviews to better understand why itch is underreported in CKD.

Material and Methods

We used the Consolidated Criteria for Reporting Qualitative Health Research.[25]

Participant Selection

Patients were eligible if they 1) were under the care of a nephrologist; 2) self-reported having been bothered by itch in the last three years; and 3) understood and spoke English. For the interviews with health care professionals, we recruited consultant and trainee nephrologists and renal nurses from three kidney centers in the U.K. Local research nurses purposively selected and invited eligible participants, aiming for a maximum variation in age, gender, treatment modality (CKD Stages 1–5, dialysis, and transplanted), and itch experience (current and past).[26]

Data Collection

We conducted face-to-face, semi-structured individual interviews with patients and nephrologists; nurses participated in focus group interviews. We developed topic guides using previous studies on barriers to symptom reporting and management;[23,27] the Common Sense Model (CSM) of self-regulation, which is a theoretical model of processes underlying the self-management of symptoms and other health threats in everyday life;[28,29] and input from two patient representatives and two nephrologists (HR and JOB). The patient guide included topics such as the impact of itch on everyday life, experiences of reporting itch to health professionals, and reasons for not reporting itch. For health care professionals, topics were experiences of patients reporting itch, perceived importance of itch as part of overall kidney care, and approaches to diagnosing and managing itch. All interviews were audio-recorded and transcribed verbatim.

Data Analysis

We uploaded transcripts into NVivo (version 11, QSR International Pty Ltd., Melbourne, Australia, 2014) to support data management and analysis. The framework method informed a two-stage data analysis strategy.[30] First, we developed and finalized a matrix that included both theory-driven codes, as well as those related to emerging themes from the first 15 interview transcripts. To pilot-test and further refine the matrix, two researchers (GA and SNvdV) independently coded five patient and three health care professional interviews, and resolved discrepancies through discussion. For all codes, the inter-rater agreement between coders was above 80% and Cohen's $\kappa \geq 0.40$.[31] Second, we used the final matrix to code the remaining transcripts. We reached data saturation after analyzing the 21st and 11th patient and health care professional transcript, respectively. Codes were described conceptually and discussed by the research team to identify iteratively cross-cutting themes between patient and health care professional interviews (i.e., participants' triangulation). Once we agreed on themes and subthemes, input from two patient representatives aided the interpretation of findings and ensured themes reflected the patients' perspective (i.e., member checking).

Results

Of the 41 patients approached, 25 (61%) agreed to be interviewed. Reasons for declining participation were as follows: unable to schedule the interview

Table 1
Participants' Characteristics

Characteristic	Number (%)
Patients	
Total *N*	25 (100)
Male gender	14 (56)
Age, yrs	
≤50	6 (24)
51–70	9 (36)
>70	10 (40)
Treatment modality	
CKD Stages 1–5[a]	6 (24)
Dialysis	14 (56)
Transplanted	5 (20)
Currently bothered by itch	20 (80)
Health care professionals	
Total *N*	22 (100)
Role	
Nephrologist	10 (45)
Renal nurse	12 (55)
Male gender	6 (27)
Years of clinical practice	
≤10	3 (14)
10–20	5 (23)
>20	2 (9)
Unknown[b]	12 (55)
Clinical area[c]	
CKD Stages 1–5	6 (24)
Dialysis/Transplant	19 (76)

CKD = chronic kidney disease.
[a]Patients who were under the care of a nephrologist, but were not on kidney replacement therapy. Half of the participants in this group were recruited from low clearance clinics, and the other half from general nephrology clinics.
[b]We did not record the years of clinical practice for nurses participating in the focus groups.
[c]Sum more than the total *N* because some health care professionals worked in more than one area.

($N = 10$); loss of interest in the study ($N = 4$); and health-related reasons ($N = 2$). Ten nephrologists and 12 renal nurses took part in the health care professional interviews. Table 1 displays participants' characteristics. Patient and nephrologist interviews lasted 15 to 72 (mean, 33.6) and 22 to 54 (mean, 33.0) minutes, respectively. The three focus groups with nurses took 24, 30, and 33 minutes.

We identified the following three main themes reflecting factors that may influence whether patients discuss itch with their kidney health care team: knowledge on causes and treatment of itch (lack of awareness of the relationship between itch and CKD, and lack of knowledge of treatment options); attitudes toward the importance of itch as a health issue (patients' and health care professionals' attitudes); and prompts for itch assessment during consultations (routine practice, itch as a marker, and itch severity). Table 2 and Appendix Table 1 contain illustrative quotations.

Knowledge on Causes and Treatment of Itch

Lack of Awareness of the Relationship Between Itch and CKD. Several patients reported that they had long been unaware that itch might be a symptom of their kidney disease, partly because the kidney team had not mentioned itch as a CKD symptom.

> *I've been itching for two years […] when I mentioned it [to the nephrologist, it was because] I had found it in a leaflet and I thought: 'that's the first time I've seen it'.* (PCe04, male, 72 years, dialysis)

Instead, patients attributed it to other conditions, such as dry skin. Accordingly, they sought help from non-kidney health care professionals, such as general practitioners (GPs) or dermatologists; nephrologists' accounts confirmed this by suggesting that many patients had already discussed itch with their GP before bringing it up in a consultation with their kidney team. However, non-kidney health care professionals often seemed similarly unaware of the relation between itch and kidney disease, potentially resulting in ineffective treatment (e.g., treating it as a mere skin condition).

Lack of Knowledge of Treatment Options. Despite realizing that itch was a consequence of having CKD, patients refrained from reporting itch to the kidney team because they assumed there was no treatment available; this emerged from both patient and health care professional interviews.

> *Interviewer: 'Have you ever discussed itch with the renal team?' Participant 'No [laughs], you just think that there's nothing they can do about it.* (PCe20, female, 58 years, transplanted)

In addition, nephrologists considered itch a difficult-to-treat symptom, which may have contributed to their reluctance to bring up itch in conversations with patients.

> *Is there a utility in acknowledging the importance of a symptom during the consultation even if it's not something that I can treat? Maybe [discussing itch] does put me off but I don't think it's necessarily without value.* (CLe04, male, consultant, 15 years clinical experience)

Some health care professionals mistakenly assumed that itch was caused by poor phosphate control, and included phosphate binders as part of their symptom management strategy.

Attitudes Toward the Importance of Itch as a Health Issue

Patients' Attitudes. Both patients and health care professionals acknowledged that itch could have a substantial impact on patients' sleep, and social and emotional well-being. However, patients said that the time they had with their nephrologist was too limited to discuss all ongoing health issues, thereby leaving itch unreported.

Table 2
Illustrative Quotations by Theme

Subtheme	Quotations
	Knowledge on causes and treatment of itch
Lack of awareness of the relationship between itch and CKD	**Patients** *"I went to my own GP […] but […] she didn't relate it to [my kidney disease]. She just put it down to like, oh, you're itching."* (PCe04, male, 72 yrs, dialysis) **Health care professionals** *"Many of them, umm, either don't refer to it at all to us, or go to the GP, because they often feel that it's not related to their kidney problem."* (CLi01, male, consultant, 23 yrs clinical experience)
Lack of knowledge on treatment options	**Patients** *"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 … to ease the pain and, you know, they ease the itching; which it hasn't helped so far, so I've just got to get on with it."* (PLi06, female, 77 yrs, CKD Stages 1−5) **Health care professionals** *"When I've asked patients why they haven't brought it up they'll say: 'Well, I didn't think you could do anything about it'."* (CLi02, female, consultant, 17 yrs clinical experience) *"[My approach to treating itch is] redoubling efforts on dialysis adequacy and phosphate"* (CLe04, male, consultant, 15 yrs clinical experience)
	Attitudes toward the importance of itch as a health issue
Patients' attitudes	**Patients** *"It got me down to the point, you know […] I'd do anything to try and stop the itching, um, and it was becoming an obsession."* (PLi04, female, 69 yrs, CKD Stages 1−5) *"It's not one of the utmost or the foremost of people's thoughts, an itch is just an itch […] It's not, like, ehmm, passing blood or I couldn't move or I couldn't walk, ehmm, I was in that much pain, I couldn't sleep, you know, it's just an itch."* (PCe13, male, 41 yrs, transplanted) *"Each time I went to the hospital, they said they would try something else. That the doctor gave me something for the itch, it didn't work, cetirizine, I think. And then I went back to the hospital last Thursday, and she said she's going to recommend using Gabapentin. […] That didn't work."* (PLi06, female, 77 yrs, CKD Stages 1−5) *"It does bother me but I just don't … I've just never mentioned it and say I'm itching you know. […] Just at my age put up with things."* (PCe07, female, 80 yrs, dialysis) **Health care professionals** *"I guess if you've got an itch and you can't sleep and you get tired and you get a low mood then in actual fact that is hugely significant really."* (CLe05, male, consultant, 5 yrs clinical experience) *"That's typically true of patients on dialysis where so many other symptoms are more bothersome [than itch]and tend to take precedence in management over management of itch."* (CMa02, female, consultant, 12 yrs clinical experience)
Health care professionals' attitudes	**Patients** *"I think it's pretty low down their list of important things […]. They are extremely busy."* (PCe08, female, 68 yrs, dialysis) *"I did say [to the nephrologist] that I was very itchy […], but it wasn't [pause] a big issue to her really."* (PCe06, female, 65 yrs, dialysis) *"Whilst I can't thank the renal team enough for everything that they're doing for me, I do think that they at times have been slightly dismissive of, you know, subjective reports of things like itches."* (PCe16, male, 60 yrs, transplanted) **Health care professionals** *"I don't actively ask about itch. I wait for patients to mention it themselves […] in the grand scheme of things, I guess [pause] it's not one of the priorities, rightly or wrongly, when I'm assessing someone with advanced CKD."* (CLe02, male, consultant, 14 yrs clinical experience) *"I suppose some patients will just feel stupid, saying, I'm itchy. It doesn't feel like something you should be telling your doctor, compared to the bigger things. You wouldn't really go to your doctor and say: 'I'm itchy', unless it was driving you seriously bonkers."* (Nurse, focus group #3)
	Prompts for itch assessment during consultations
Routine practice	**Patients** *"I had to tell them. I said: 'I've got this itch'."* (PLi03, male, 74 yrs, CKD Stages 1−5) *"They [the renal nurses] always ask about it when I attend the clinic."* (PLi05, female, 72 yrs, CKD Stages 1−5) **Health care professionals** *"I don't think we're at the point where … either in an outpatient clinic or during the dialysis session I don't think it forms part of the standard question to the patient."* (CLi04, male, consultant, 15 yrs clinical experience) *"Itch would be definitely one of my routine questions."* (CMa02, female, consultant, 12 yrs clinical experience)
Itch as a marker	**Health care professionals** *"Interviewer: 'Is itch something that you directly ask about? Nephrologist: 'Yes, I do, especially in pre-dialysis clinic because I consider it a marker of the uraemia."* (CLe10, male, consultant trainees, 4 yrs clinical experience) "*I would bring [phosphate] up as an excuse to be able to try to link a symptom [itch], which somebody might have, with a goal which I'm trying to achieve […] which is actually the phosphate.*" (CLi04, male, consultant, 15 yrs clinical experience)
Itch severity	**Patients** *"Sometimes I don't ask about stuff, sometimes I just put up with things […] and then, umm, obviously it gets worse, so then I've got no choice, I … you know, to … to say to somebody."* (PCe05, male, 58 yrs, dialysis) *"Interviewer: 'Why did you think that the GP was the right person to talk about your itch?' Patient: 'Well, er, I … I think it was more a matter of timing, than anything else […] I happened to have a GP appointment, and, and I was being particularly bothered at that time'."* (PCe08, female, 68 yrs, dialysis) **Health care professionals** *"Most patients don't report themselves, okay? […] but when you ask them, most of them say: 'yeah, I do suffer from itching'. The people that have very severe itch, of course, they volunteer and they ask for help."* (CLi01, male, consultant, 23 yrs clinical experience) *"I think there probably is a tendency to dismiss it as not necessarily as important unless it's been a real problem in the few days before."* (CLe08, female, consultant, 4 yrs clinical experience)

CKD = chronic kidney disease; GP = general practitioner.

In the early days, I mentioned [itch], but I usually have so much to talk about that it isn't something that has come up in recent times. (PCe08, female, 68 years, dialysis)

This was in line with health care professionals suggesting that patients—especially those on dialysis or with multimorbidity—might engage in a process of prioritizing symptoms in which discussing other, more worrisome, symptoms prevailed.

If somebody is struggling with their health in some of the, as you say, life threatening or […] something else concrete and I could imagine for everybody [itch] slips down their agenda. (CLe04, male, consultant, 15 years clinical experience)

Many patients who prioritized other health issues during consultations said they had come to accept itch as something they had to live with; an attitude that might have been reinforced by health care professionals.

[The nurse] sort of advised me: 'well, when your kidney functions go down you get problems like that'. I think it was like an acceptance these things happen, and just let me know that, you know, that's what to expect. (PLi12, male, 55 years, dialysis)

Other reasons for this accepting attitude included seeing itch as something trivial, a history of unsuccessful treatments, or fear of being prescribed additional medications.

Health Care Professionals' Attitudes. Also, health care professionals described how they dismissed the importance of itch in favor of other symptoms and health issues. They acknowledged that their attitudes toward itch or symptoms in general might have influenced whether or not patients brought it up during the consultation. Some argued that patients may censor themselves because they anticipate that their nephrologist finds other issues more important; does not consider itch worth discussing; or will not take them seriously.

A fair number of people mention [itch], but then perhaps move on to other things that either they think are more important or they think that I will think are more important. (CLe08, female, consultant, four years clinical experience)

This was confirmed in the patient interviews, where people said they had noticed that health care professionals did not consider itch a priority, or were more interested in the objectively measured aspects of CKD.

The impression I get is that the renal team see a patient like me that's had no changes or fluctuation of body chemistry since the transplant, the drugs are stable, the graft is working well, therefore why would you consider getting involved in any other issues? (PCe17, male, 32 years, transplanted)

Prompts for Itch Assessment During Consultations

Routine Practice. From both patients' and health care professionals' accounts, it was apparent that symptom assessment practices varied widely between health care providers. Whereas many patients said they had to raise the issue themselves, others were routinely asked at clinic visits. And despite most renal nurses and nephrologists being aware of itch remaining unreported, many expected patients to bring it up, with only a few saying they would systematically ask about it.

I've got the script I've got to get to the end of and I hope I give the patients enough time to get to […] at least a fair amount of whatever their script is. […] I don't bring that up as a specific 'do you itch?', with a patient. So, that's nowhere on my list at all. (CLe04, male, consultant, 15 years clinical experience)

At the same time, patients expected members of the kidney team to raise the issue:

Probably from my point of view, it would be a good idea if the consultants just listed that as one of the questions they ask. (PCe08, female, 68 years, dialysis)

Itch as a Marker. Several nephrologists considered itch as a marker of uremia and therefore asked about the symptom in pre-dialysis settings to inform the decision whether to start dialysis.

In a dialysis population, it wouldn't be one of the questions that I would routinely ask actually, because I guess probably I would view itch in a pre-dialysis setting as, you know, a sign that people may need to start dialysis. (CLe05, male, consultant, 5 years clinical experience)

Health care professionals who thought itch was caused by high serum phosphate levels discussed the symptom as part of a strategy to motivate patients to better manage their phosphate.

Itch Severity. Patients and health care professionals suggested that itch might only be discussed after reaching a certain level of severity; for example, when resulting in sleep deprivation or skin damage.

If it stops me sleeping, I would tell them (PLi01, male, 80 years, dialysis)

Furthermore, patients indicated that itch severity fluctuated over time. And as periods of severe itching did not always coincide with seeing the nephrologist,

patients would seek help from other health care professionals, such as their GP or renal nurses. In addition, health care professionals suggested that patients may not recall being itchy when visiting the renal unit if the symptom was not bothering them at the time.

> *By the time they get to us, they might have forgotten that they've got this itch, and they're only with us for a short duration, four hours.* (Nurse, focus group #3)

Discussion

Summary of Findings

We interviewed 25 CKD patients and 22 kidney health care professionals to explore why uremic pruritus—or itch—is not discussed between patients and their kidney team, therefore risking underidentification and suboptimal management. Reasons for underreporting were related to the following: knowledge of causes and treatment of itch; attitudes toward the importance of itch as a health issue; and prompts for itch assessment during consultations. Our findings provide clear pointers for how to improve itch reporting and management.

Relation to Other Studies

Our findings overlap with those of a qualitative study from the U.S. by Flythe et al. of views on symptom experiences and reporting of 42 hemodialysis patients and 13 dialysis nurses and technicians.[32] This suggests that some reasons for underreporting may be similar across symptoms, disease stages, treatment modalities, and health care professionals, such as lack of knowledge on what causes symptoms and how to manage them; seeing symptoms as an unavoidable consequence of kidney disease; dismissive attitudes from health care professionals; competing health issues and professional demands; and health care professionals expecting patients to bring symptoms up during a consultation. Related to the latter, our study additionally found that patients also expected health care professionals to ask about symptoms, and that they assumed the absence of a clinician's prompt to imply that symptoms did not warrant discussion.

Inclusion of nephrologists and non-dialysis CKD patients in our sample may explain why some of the reasons in our "prompts for itch assessment" theme were not identified by Flythe et al. For example, we found that itch might remain undiscussed if it is not severe at the time of the clinic encounter. This is more likely in people who have an outpatient visit every three months, compared with those who come to the dialysis unit three times a week. We also identified variation in whether and how symptoms were assessed, which may indicate that the role of symptoms in disease management differs between stages of CKD severity and types of health care professionals.

Relation to Theory

We used the CSM of self-regulation as the theoretical framework to guide data collection and analysis. It poses that people's beliefs about their illness (i.e., illness representations) enables them to make sense of symptoms, and that this affects coping strategies, which in turn impacts on health outcomes.[28,29] Not reporting symptoms may reflect a negative or passive-avoidant coping strategy. Therefore, to support patients adopt more positive coping strategies to improve their symptom burden, quality of life and other outcomes, we should address reasons for underreporting that are related to people's illness representations.

One reason for underreporting identified in our study was patients' lack of knowledge on the relation between CKD and itch. This links to CSM's *cause* component, which refers to people's individualistic ideas about the perceived cause of a condition. CSM proposes that enhancing this knowledge would improve ability to self-regulate, and thus the likelihood that people will engage in self-reporting as part of an active coping approach.[28] The latter may also be achieved through strengthening patients' beliefs that itch could be controlled (CSM's *controllability* component), for example, through an intervention that prompts health care professionals to ask about itch and suggests recommended treatments. This would avoid the impression that itch is untreatable and thus not worth discussing.

Implications for Clinical Practice

We suggest three ways to improve reporting and management of itch, and also of CKD symptoms more generally.

Include Information on Symptoms in Pre-Dialysis Education. Although symptoms are often mentioned in patient information on CKD,[33,34] they may be absent in materials that inform people on dialysis and other forms of kidney replacement therapy (KRT).[35] As KRT does not always relieve itch and other symptoms, this absence of information negatively affects patients' awareness that some symptoms may be related to CKD and its treatment. Including symptom information as part of pre-KRT education may enhance this understanding[23,33,36] and thereby the likelihood that people will discuss their symptoms with others.

Develop Clinical Practice Guidelines on Itch Management. Not knowing how to treat itch led health care

professionals in our study to report avoiding discussing it in consultations. Some tried to manage itch by lowering phosphate levels, but no randomized controlled trials have been conducted to evaluate the effectiveness of this strategy, nor have large observational studies confirmed an association between elevated phosphate levels and itch.[12] However, there is sufficient evidence available on other treatments to warrant development of clinical practice guidelines on itch management.[16,33] If successfully developed and implemented,[37] such guidelines would likely improve knowledge among health care professionals of evidence-based treatment options.

Incorporate Systematic Symptom Assessments into Kidney Routine Care. We found that clinical practice of itch assessment varied widely. Incorporating systematic symptom assessments into care would reduce this variation and prompt shared decisions between patients and professionals about symptom management. Routine symptom assessments have been advocated by many others[23,32,33,38–41] based on evidence that it enhances identification of problems and patient-clinician communication, reduces symptom burden and distress, and improves quality of life.[42,43]

Proposed ways include the use of validated questionnaires,[44,45] electronic data collection,[38] and incorporating feedback of results within existing clinical systems.[36] To support health care professionals with making sense of symptom information quickly, scores could be combined with contextual information, such as laboratory results, or with alerts to indicate which symptoms require most attention.[36] Our findings suggest that pre-dialysis might be a suitable context to initiate this practice change because health care professionals often already consider symptoms when deciding whether to start KRT.[46] Local initiatives aimed to implement systematic, electronic symptom assessments in CKD care have been reported,[47–49] but further efforts are warranted to achieve this at a larger scale.

Strengths and Limitations

To our knowledge, this is the first in-depth qualitative study to investigate reasons for underreporting of itch among people with CKD across stages and treatment modalities. Interviewing both patients and health care professionals, and triangulating perspectives between them, increased our understanding of the complexity of the symptom reporting process, such as reciprocal expectations for the other party to raise itch as an issue. This enabled us to provide clear pointers for how to facilitate the reporting process and improve management of itch and potentially other symptoms.

A limitation of our study is that our participants were predominantly white British and all able to speak English, which hampered investigating cultural and language barriers as a reason for underreporting. In addition, we might not have captured the full range of experiences with regard to itch reporting patients and health care professionals in our study were likely to be aware of itch as a symptom of CKD and to perceive it as a topic that is worth discussing. Although we do not anticipate that recruiting participants with a wider range of experiences and perspectives would have resulted in different themes, we might have been able to add more depth to the themes related to "knowledge on causes and treatment" and "attitudes toward importance of itch."

Conclusion

Underreporting of itch is related to patients' lack of awareness of its link with kidney disease, and to their acceptance of itch as something they have to live with. Furthermore, the length and timing of consultations may lead them to prioritize other health issues. Health care professionals' assessment and management strategies vary widely and are not necessarily evidence-based. Better patient information, development of clinical practice guidelines, and incorporating systematic symptom assessments into care may improve itch reporting and management in people with CKD.

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The authors declare that they have no competing interests, and that the results presented in this article have not been published previously in whole or part, except in abstract format.

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Appendix

Appendix Table 1
Additional Illustrative Quotations for Each Theme

Subtheme	Quotations
	Knowledge on causes and treatment of itch
Lack of awareness of the relationship between itch and CKD	**Patients**
	"[During the pre-dialysis meetings] they were discussing … like showing you all the various things [different options of dialysis], but they never discussed itching." (PLi12, male, 55 yrs, dialysis)
	"I didn't know [itch] had anything to do with the kidneys but I was certainly never told." (PLi08, female, 77 yrs, CKD Stages 1–5)
	Clinicians
	"I also think a lot of renal patients are not aware that it's a problem to do with their renal failure, partly because we don't tell them." (CLi02, female, consultant, 17 yrs clinical experience)
	"Most patients, by the time they say to us they've got itching, they've tried various creams and things, quite often they've been treated by the GP with antihistamine tablets." (CLi01, male, consultant, 14 yrs clinical experience)
	"I would think that they just try and go to their GP and try and see if they can manage with, you know, the various creams." (CMa02, female, consultant, 12 yrs clinical experience)
Lack of knowledge on treatment options	**Clinicians**
	"Because itchiness is very difficult [to treat] … first of all, you need to find out what is the cause of the itching, if you can do. And then, to try and treat it symptomatically." (CMa01, female, consultant, 31 yrs clinical experience)
	"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." (CLi01, male, consultant, 23 yrs clinical experience)
	"Antihistamines […] I don't find that they're necessarily useful." (CMa02, female, consultant, 12 yrs clinical experience)
	"It is recognised that a raised phosphate level can be associated with itchiness. We have a dietitian resident in our clinic, so they would get dietetic advice regarding reduced phosphate intake." (CMa01, female, consultant, 31 yrs clinical experience).
	"[Itch] is more important now, now that we know there's something that can be done about it." (nurse, focus group #1)
	Attitudes toward importance of itch as a health issue
Patients' attitudes	**Patients**
	"*[I am embarrassed] because if you're itching and things people think: 'Oh, is he dirty? Has he got scabies?'*." (PCe04, male, 72 yrs, dialysis)
	"[I did not report it because] I thought it was a trivial symptom not worth mentioning." (PLi01, male, 41 yrs, dialysis)
	"An itch is just an itch." (PCe13, male, 41 yrs, transplanted)
	"I just kind of … I've got to the stage where I just think it's one of those things that I'll just live with." (PCe17, male 32 yrs, transplanted)
	"Interviewer: 'Have you mentioned itch to your nephrologist recently?' Patient: 'Only the first time […] Because I'm taking so many pills already, I'm frightened that if I go and say, something else is, is happening, that's another pill'." (PLi05, female, 72 yrs, CKD Stages 1–5)
	Clinicians
	"I'd say itch is quite important because you see the difference once they've been treated … because they're sleeping and they're not scratching all the time they're like different people." (nurse, focus group #1)
	"It is important because […] it is one of the symptoms that impair quality of life of dialysis." (CLi01, male, consultant, 23 yrs clinical experience)
	"Patients don't only require one drug, you know, they require several […]. So, […] perhaps that symptom [itch] is not as constant during the day, they are overwhelmed by all issues regarding the uraemia […]. They would be, perhaps, more afraid to dying of something else rather than the itching." (CLe10, male, trainee nephrologist, 4 yrs clinical experience)
Clinicians' attitudes	**Patients**
	"[The nephrologist] said: 'Well, don't worry about it', and that was his answer." (PLi10, female, 89 yrs, dialysis)
	"I thought: 'Well it [itch] mustn't be serious because I've never been talked serious', but it is sometimes quite bad." (PCe06, female, 65 yrs, dialysis)
	"I think here they care creatinine levels more than itching." (PCe13, male, 41 yrs, transplanted)
	"I think it was viewed as quite a minor thing, really. […] they think: 'Well, you've got bigger things to think about'." (PCe16, male, 60 yrs, transplanted)
	Clinicians
	"If you look at the priorities […] nobody dies of itch. […] the quality of life issue is a big problem, but […] it's not the breathing and the ankles that, you know, the nursing staff would talk about." (CLi02, female, consultant, 17 yrs clinical experience)
	"As a symptom it is part of a list of things which are probably more important to the patient than they are to their doctors." (CLe04, male, consultant, 15 yrs clinical experience)
	"I'm more interested in weight loss, appetite, nausea, vomiting, and other kinds of uraemic symptoms." (CLe02, male, consultant, 14 yrs clinical experience)
	"I think it's quite easy to get focused on the things that I perceive as potentially life threatening and forget that actually [hesitation] severe itching is a very intrusive." (CLe08, female, consultant, 4 yrs clinical experience)
	"It's very problematic for patients but I think a lot of doctors and … or health care professionals in general don't tend to bring it up or don't think it's a problem." (CLi02, female, consultant, 17 yrs clinical experience)
	"I think any symptom management is very relevant. And itching is something that can stop people sleeping. And, obviously be very embarrassing, and uncomfortable during the day […] we're trying to symptom manage, and improve their quality of life." (CMa01, female, consultant, 31 yrs clinical experience)

(*Continued*)

Appendix Table 1
Continued

Subtheme	Quotations
	"And for trainees, I think they don't get brought up to recognise that actually itch is a significant […] the same for renal nurses." (CLi02, female, consultant, 17 yrs clinical experience)
	"I guess it depends on how willing both parties are to space to talk about that sort of thing and because with the space I suspect it comes out and without the space it's probably not on the list of things which the patient thinks the doctor's going to be interested in." (CLe04, male, consultant, 15 yrs clinical experience)
	Prompts for itch assessment during consultations
Routine practice	**Patients**
	"They just ask me the standard questions: 'Are you still itchy?', and I'll put, yes, and they suggest things'." (PLi07, male, 48 yrs, CKD Stages 1–5)
	Clinicians
	"It's not something that's formalised. It's not that I've got a checklist that I tick off or that we have a pro forma or a symptom scoring." (CLe01, male, consultant, 23 yrs clinical experience)
	"We ask every time we see the patient in an out-patient setting, we ask them about itching […] and we ask them to grade it as well." (CLi01, male, consultant, 14 yrs clinical experience)
	"I think for patients it's a major issue and I think a lot of patients would welcome it. How this would fit in in my everyday care? but then my everyday care might be very different from everyday care of another clinician, just because I'm acutely aware it's an issue." (CLi02, female, consultant, 17 yrs clinical experience)
	"My standard approach in clinic is to ask the patient how they're doing and then if they don't volunteer any symptoms, to run through very quickly a list of symptoms that they might have, tiredness, breathing difficulty, changes in appetite, er, nausea, vomiting, changes in taste, itching. Now, I'm not saying I do that with every single patient, but if the patient, er, either doesn't report any symptoms or, um, says they feel well, I usually try to elicit […]in the pre-dialysis clinic. Whereas I wouldn't normally do it in the general nephrology clinic, because I suppose my prejudice is that I won't find … most of these patients won't have these symptoms." (CLe01, male, consultant, 23 yrs clinical experience)
	"I think most of us are acutely aware that itch is a big problem with patients and most of them won't bring it up." (CLi02, female, consultant, 17 yrs clinical experience)
	"A small number of patients voluntarily report it as a very troublesome symptom. Other patients report it as a symptom, but I'm sure where you actively seek it as a symptom, you will probably find other patients who don't volunteer it." (CLi01, male, consultant, 23 yrs clinical experience)
Itch as a marker	**Clinicians**
	"Itching is something that I will [talk about] […] in a pre-dialysis setting, particularly when I'm discussing at what point patients might need dialysis [along with] appetite, nausea, vomiting, generalised itching, all of the kind of uremic symptoms." (CLe08, female, consultant, 4 yrs clinical experience)
Itch severity	**Patients**
	[Itch] comes and goes, ehmm, sometimes it is particularly bad, stops you sleeping." (PCe17, male, 32 yrs, transplanted)
	"It would give up a bit, you know, then it has come back again and, you never had many days of peace." (PLi03, male, 74 yrs, CKD Stages 1–5)
	"The only reason why I got treated is because it was visual, you could visually see the skin was broken." (PCe13, male, 41 yrs, transplanted)
	"You deal with the nurses mostly, and the consultant only comes in if they're a bit unsure on anything. […] We don't really see the consultant very often, do we?, unless it's an emergency, or I'm in a lot of pain […] maybe once a year, twice a year." (PLi07, male, 48 yrs, CKD Stages 1–5)
	Clinicians
	"Very often they don't [report itch], and when they do, you can actually see evidence of scratch marks on their physical body, and I think you then ask: 'Have you been scratching yourself?', that's when they probably start with the story of the itch." (CMa02, female, consultant, 12 yrs clinical experience)

CKD = chronic kidney disease; GP = general practitioner.