

Reasons for underreporting of uraemic pruritus in people with chronic kidney disease: A qualitative study

G. Aresi, H.C. Rayner, L. Hassan, J.O. Burton, S. Mitra, C. Sanders, S.N. Van der Veer



PII: S0885-3924(19)30343-4

DOI: <https://doi.org/10.1016/j.jpainsymman.2019.06.010>

Reference: JPS 10153

To appear in: *Journal of Pain and Symptom Management*

Received Date: 29 April 2019

Revised Date: 11 June 2019

Accepted Date: 11 June 2019

Please cite this article as: Aresi G, Rayner H, Hassan L, Burton J, Mitra S, Sanders C, Van der Veer S, Reasons for underreporting of uraemic pruritus in people with chronic kidney disease: A qualitative study *Journal of Pain and Symptom Management* (2019), doi: <https://doi.org/10.1016/j.jpainsymman.2019.06.010>.

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Reasons for underreporting of uraemic pruritus in people with chronic kidney disease:**A qualitative study**

Aresi G¹, Rayner HC², Hassan L¹, Burton JO³, Mitra S^{4,5}, Sanders C^{6,7}, Van der Veer SN¹

¹ Centre for Health Informatics, Division of Informatics, Imaging and Data Sciences, Faculty of Biology, Medicine and Health, Manchester Academic Health Science Centre, The University of Manchester, Manchester, UK

² University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK

³ University Hospitals of Leicester NHS Trust, Leicester, UK

⁴ Manchester Academy of Health Sciences Centre, Manchester University Foundation Hospitals

⁵ NIHR Devices for Dignity Med Tech Co-operative

⁶ National Institute for Health Research School for Primary Care Research, The University of Manchester, Manchester, UK

⁷ National Institute for Health Research Greater Manchester Patient Safety Translational Research Centre, The University of Manchester, Manchester, UK

Corresponding author

Dr Sabine van der Veer

University of Manchester

Centre for Health Informatics

Vaughan House

Portsmouth Street

Manchester

M13 9GB

United Kingdom

Email: sabine.vanderveer@manchester.ac.uk

Phone: + 44 161 306 7767

Manuscript type:	Original article
Word count:	3,350 (excl. abstract, references, tables and figures)
Abstract:	250
Figures/tables:	2
References:	49

Abstract

Context

Uraemic 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 in order 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 United Kingdom. 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 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; lack of knowledge of treatment options); attitudes towards importance of itch as a health issue (patients' attitudes; clinicians' attitudes); and prompts for itch assessment during consultations (routine practice; itch as a marker; itch severity).

Conclusions

Underreporting of itch is related to patients being unaware of its causes, accepting it as something to live with, prioritising other health issues, and the length and timing of consultations. Healthcare 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.

Keywords (max 5)

Chronic kidney disease; Uraemic pruritus; Patient-generated health data; Symptom management;

Qualitative research

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 unrecognised and untreated (10–12).

Uraemic pruritus, or itch, is a common, yet often overlooked CKD symptom, with estimated prevalence ranging from 25% (13) to 44% (14). Whilst 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 moisturisers, topical ointments and Gabapentin (16–18). Nonetheless, 20% of severely affected patients in a large cohort study –the Dialysis Outcomes and Practice Patterns Study (DOPPS)—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).

Healthcare 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 DOPPS said they had never discussed their itch with a healthcare 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 healthcare professionals view, discuss and manage itch. Therefore, we conducted a qualitative study that combined patient and healthcare 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 (i) were under the care of a nephrologist; (ii) self-reported having been bothered by itch in the last three years; and (iii) understood and spoke English. For the interviews with healthcare professionals, we recruited consultant and trainee nephrologists and renal nurses from three kidney centres in the UK. Local research nurses purposively selected and invited eligible participants, aiming for a maximum variation in age, gender, treatment modality (CKD stage 1-5; dialysis; transplanted) and itch experience (current; 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 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 healthcare 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., 2014) to support data management and analysis. The Framework Method informed a two-stage data analysis strategy (30).

First, we developed and finalised a matrix that included both theory-driven codes, as well as those related to emerging themes from the first fifteen interview transcripts. To pilot-test and further refine the matrix, two researchers (GA and SvdV) independently coded five patient and three healthcare professional interviews, and resolved discrepancies through discussion. For all codes, the inter-rater agreement between coders was above 80% and Cohen's $\kappa \geq .40$ (31). Second, we used the final matrix to code the remaining transcripts. We reached data saturation after analysing the 21st and 11th patient and healthcare professional transcript, respectively. Codes were described conceptually and discussed by the research team to identify iteratively cross-cutting themes between patient and healthcare 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).

Ethical approval

The study was approved by the UK Health Research Authority's Research Ethics Service, East Midlands – Leicester South Research Ethics Committee (IRAS ID 220320).

Results

Of the 41 patients approached, 25 (61%) agreed to be interviewed. Reasons for declining participation were: unable to schedule the interview (N = 10); loss of interest in the study (N = 4); health-related reasons (N = 2). Ten nephrologists and twelve renal nurses took part in the healthcare 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.

[Insert Table 1 here]

We identified the following three main themes reflecting factors that may influence whether patients discuss itch with their kidney healthcare team: knowledge on causes and treatment of itch (lack of awareness of the relationship between itch and CKD; lack of knowledge of treatment options); attitudes towards the importance of itch as a health issue (patients' attitudes; healthcare professionals' attitudes); and prompts for itch assessment during consultations (routine practice; itch as a marker; itch severity). Table 2 and supplemental Table S1 contain illustrative quotations.

[Insert Table 2 here]

Knowledge on causes and treatment of itch

Lack of awareness of the relationship between itch and CKD

Several patients reported 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 healthcare 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 healthcare 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 realising 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 healthcare 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 healthcare professionals mistakenly assumed that itch was caused by poor phosphate control, and included phosphate binders as part of their symptom management strategy.

Attitudes towards the importance of itch as a health issue

Patients' attitudes

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

“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 healthcare professionals suggesting that patients – especially those on dialysis or with multimorbidity — might engage in a process of prioritising 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 prioritised 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 healthcare 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, 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.

Healthcare professionals’ attitudes

Also healthcare professionals described how they dismissed the importance of itch in favor of other symptoms and health issues. They acknowledged that their attitudes towards 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, 4 years clinical experience)

This was confirmed in the patient interviews, where people said they had noticed that healthcare 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 healthcare professionals' accounts, it was apparent that symptom assessment practices varied widely between healthcare 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 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)

Healthcare 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 healthcare 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 since periods of severe itching did not always coincide with seeing the nephrologist, patients would seek help from other healthcare professionals, such as their GP or renal nurses. Additionally, healthcare 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 healthcare professionals to explore why uraemic pruritus – or itch — is not discussed between patients and their kidney team, therefore risking under-identification and suboptimal management. Reasons for underreporting were related to: knowledge of causes and treatment of itch; attitudes towards 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 United States 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 healthcare 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 healthcare professionals; competing health issues and professional demands; and healthcare professionals expecting patients to bring symptoms up during a consultation. Related to the latter, our study additionally found that patients also expected healthcare 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 to 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 healthcare professionals.

Relation to theory

We used the Common Sense Model (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 healthcare 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

Whereas 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). Since 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 healthcare professionals in our study to report avoiding discussing it in consultations. Some tried to manage itch by lowering phosphate levels, but no randomised 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 healthcare 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 healthcare 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 healthcare 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 healthcare 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 healthcare 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 towards 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 prioritise other health issues. Healthcare 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.

Acknowledgements

We would like to thank all patients and healthcare professionals who participated in our study. We are particularly grateful to Mrs. Vanessa van Wyk and Mr. Anthony Albrow, our patient representatives, for sharing their thoughts and feedback throughout the study. We also acknowledge Hollie Walton and Amanda Insley for their support with participant recruitment.

Conflict of interest statement

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

Authors' Contributions

SV conceived the idea for the study. GA, HR, JB, LH, CS and SV designed the study. HR, SM and JB supported recruitment of participants. GA conducted the interviews and analysed the data. All authors were involved in interpretation of findings. GA and SV drafted a first version of the manuscript. All authors critically revised the manuscript for important intellectual content and approved the final version for publication.

Funding

This work was supported by a Kidney Research UK Innovation grant (reference IN_013_20160304).

References

1. Brown SA, Teyer FC, Clarke AL et al. Symptom burden in patients with chronic kidney disease not requiring renal replacement therapy. *Clinical Kidney Journal* 2017; 10: 788–796.
2. Senanayake S, Gunawardena N, Paliawadana P et al. Symptom burden in chronic kidney disease; a population based cross sectional study. *BMC Nephrology* 2017; 18: 228.
3. Wang R, Tang C, Chen X et al. Poor sleep and reduced quality of life were associated with symptom distress in patients receiving maintenance hemodialysis. *Health & Quality of Life Outcomes* 2016; 14: 1–8.
4. Davison SN, Jhangri GS. Impact of pain and symptom burden on the health-related quality of life of hemodialysis patients. *Journal of pain and symptom management* 2010; 39: 477–485.
5. Weisbord SD, Mor MK, Sevvick MA, Shields AM, Rollman BL, Palevsky PM. Associations of depressive symptoms and pain with dialysis adherence, health resource utilization, and mortality in patients receiving chronic hemodialysis. *Clinical journal of the American Society of Nephrology* 2014; 9: 1594–1602.
6. Manns B, Hemmelgarn B, Lillie E et al. Setting research priorities for patients on or nearing dialysis. *Clinical journal of the American Society of Nephrology* 2014; 9: 1813–1821.
7. Stevens PE, Levin A, for the KDIGO guideline development group. Evaluation and Management of Chronic Kidney Disease : Synopsis of the Kidney Disease : Improving Global Outcomes (KDIGO) 2012 Clinical Practice Guideline. *Annals of Internal Medicine* 2013; 158: 825–831.
8. National Kidney Foundation. KDOQI Clinical Practice Guideline for Hemodialysis Adequacy: 2015 Update. *American Journal of Kidney Diseases* 2015; 66: 884–930.
9. Davison SN, Levin A, Moss AH et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney International* 2015; 88: 447–459.
10. Weisbord SD, Fried LF, Mor MK et al. Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clinical Journal of the American Society of Nephrology* 2007; 2: 960–967.
11. Claxton RN, Blackhall L, Weisbord SD, Holley JL. Undertreatment of Symptoms in Patients on Maintenance Hemodialysis. *Journal of Pain and Symptom Management* 2010; 39: 211–218.
12. Rayner HC, Larkina M, Wang M et al. International comparisons of prevalence, awareness and treatment of pruritus in people on hemodialysis. *Clinical journal of the American Society of Nephrology* 2017; 12: 2000–2007.
13. Weiss M, Mettang T, Tschulena U, Passlick-Deetjen J, Weisshaar E. Prevalence of Chronic Itch and Associated Factors in Haemodialysis Patients: A Representative Cross-sectional Study. *Acta Dermato Venereologica* 2015; 95: 816–821.
14. Kimata N, Fuller DS, Saito A et al. Pruritus in hemodialysis patients: Results from the Japanese Dialysis Outcomes and Practice Patterns Study (JDOPPS). *Hemodialysis international. International Symposium on Home Hemodialysis* 2014; : 1–11.
15. Mettang T, Kremer AE. Uremic pruritus. *Kidney International* 2015; 87: 685–691.
16. Davison SN, Tupala B, Wasylynuk BA, Siu V, Sinnarajah A, Triscott J. Recommendations for the Care of Patients Receiving Conservative Kidney Management: Focus on Management of Chronic Kidney Disease and Symptoms. *Clinical journal of the American Society of Nephrology : CJASN [Internet]* 2019; : [Epub ahead of print]. Available from: <http://cjasn.asnjournals.org/lookup/doi/10.2215/CJN.10510917%0Ahttp://www.ncbi.nlm.nih.gov/pubmed/30819670>
17. Siemens W, Xander C, Meerpohl J et al. Pharmacological interventions for pruritus in adult palliative care patients (Review). *Cochrane database of systematic reviews* 2016; : Art.No.: CD008320.
18. Rayner H, Baharani J, Smith S, Suresh V, Dasgupta I. Uraemic Pruritus: Relief of Itching by Gabapentin and Pregabalin. *Nephron - Clinical Practice* 2013; 122: 75–79.
19. Hayani K, Weiss M, Weisshaar E. Clinical findings and provision of care in haemodialysis patients with chronic itch: New results from the german epidemiological haemodialysis itch study. *Acta Dermato-Venereologica* 2016; 96: 361–366.
20. Susel J, Batycka-Baran A, Reich A, Szepietowski JC. Uraemic pruritus markedly affects the quality of life and depressive symptoms in haemodialysis patients with end-stage renal disease. *Acta dermato-venereologica* 2014; 94: 276–281.

21. Ramakrishnan K, Bond TC, Claxton A et al. Clinical characteristics and outcomes of end-stage renal disease patients with self-reported pruritus symptoms. *International Journal of Nephrology and Renovascular Disease* 2014; 7: 1–12.
22. Mathur VS, Lindberg J, Germain M et al. A longitudinal study of uremic pruritus in hemodialysis patients. *Clinical Journal of the American Society of Nephrology* 2010; 5: 1410–1419.
23. Feldman R, Berman N, Reid MC, Roberts J. Improving Symptom Management in Hemodialysis Patients : Identifying Barriers and Future Directions. *Journal of palliative medicine* 2013; 16: 1528–1533.
24. Weisshaar E, Mattern U, Mettang T. How do nephrologists in haemodialysis units consider the symptom of itch? Results of a survey in Germany. *Nephrology, dialysis, transplantation : official publication of the European Dialysis and Transplant Association - European Renal Association* 2009; 24: 1328–1330.
25. Allison T, Peter S, Jonathan C. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 2007; 19: 349.
26. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research* 2015; 42: 533–544.
27. Bathe A, Weisshaar E, Mattern U. Chronic pruritus - more than a symptom: a qualitative investigation into patients' subjective illness perceptions. *Journal of Advanced Nursing* 2013; 69: 316–326.
28. Leventhal H, Diefenbach M. The active side of illness cognition. In: Skelton J, Croyle R, eds. *Mental representation in health and illness*. Springer Verlag, New York: 1991; 247–272
29. McAndrew LM, Mora PA, Quigley KS, Leventhal EA, Leventhal H. Using the Common Sense Model of Self-Regulation to Understand the Relationship Between Symptom Reporting and Trait Negative Affect. *International Journal of Behavioral Medicine* 2014; 21: 989–994.
30. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology [Internet]* 2013; 13: 117. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3848812&tool=pmcentrez&rendertype=abstract>
31. Mchugh ML. Lessons in biostatistics Interrater reliability : the kappa statistic. *Biochemia Medica* 2012; 22: 276–282.
32. Flythe JE, Dorough A, Narendra JH, Forfang D, Hartwell L, Abdel-Rahman E. Perspectives on symptom experiences and symptom reporting among individuals on hemodialysis. *Nephrology Dialysis Transplantation* 2018; : 1–11.
33. Brennan F, Siva B, Crail SM. ANZSN Renal Supportive Care Guidelines 2013: Appropriate assessment of symptom burden and provision of patient information. *Nephrology* 2013; 18: 418–421.
34. National Health Service. Chronic Kidney Disease symptoms [Internet]. [cited 2019 Feb 25] Available from: <https://www.nhs.uk/conditions/kidney-disease/symptoms/>
35. Mooney A, Nilsson E-L, Dean J et al. Quality standards for predialysis education: results from a consensus conference. *Nephrology Dialysis Transplantation* 2014; 30: 1058–1066.
36. Reading MJ, Merrill JA. Converging and diverging needs between patients and providers who are collecting and using patient-generated health data: an integrative review. *Journal of the American Medical Informatics Association* 2018; 25: 759–771.
37. van der Veer SN, Tomson CR V, Jager KJ, van Biesen W. Bridging the gap between what is known and what we do in renal medicine: improving implementability of the European Renal Best Practice guidelines. *Nephrology Dialysis Transplantation* 2014; 29: 951–957.
38. van der Veer SN, Aresi G, Gair R. Incorporating patient-reported symptom assessments into routine care for people with chronic kidney disease. *Clinical Kidney Journal* 2017; : [in press].
39. Brown SA, Tyrer F, Clarke AL et al. Kidney symptom questionnaire: Development, content validation and relationship with quality of life. *Journal of renal care* 2018;
40. Davison SN, Jassal SV. Supportive care: Integration of patient-centered kidney care to manage symptoms and geriatric syndromes. *Clinical Journal of the American Society of Nephrology* 2016; 11: 1882–1891.
41. Cabrera VJ, Hansson J, Klinger AS, Finkelstein FO. Symptom Management of the Patient with CKD: The Role of Dialysis. *Clinical Journal of the American Society of Nephrology* 2017; 12: 687–693.
42. Basch E, Deal AM, Kris MG et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *Journal of Clinical Oncology* 2016; 34: 557–565.
43. Johansen MA, Rosvold Berntsen GK, Schuster T, Henriksen E, Horsch A. Electronic symptom reporting between patient and provider for improved health care service quality: A systematic review of randomized controlled trials.

Part 2: Methodological quality and effects. *Journal of Medical Internet Research* 2012; 14: 1–26.

44. Flythe J, Powell J, Poulton C et al. Patient-reported outcome instruments for physical symptoms among patients receiving maintenance dialysis: a systematic review. *American journal of kidney diseases* 2015; 66: 1033–1046.
45. Almutary H, Bonner A, Douglas C. Symptom Burden in Chronic Kidney Disease : a Review of Recent Literature. *Journal of Renal Care* 2013; 39: 140–150.
46. De Goeij MCM, Ocak G, Rotmans JI, Eijgenraam JW, Dekker FW, Halbesma N. Course of symptoms and health-related quality of life during specialized pre-dialysis care. *PLoS ONE* 2014; 9: e93069.
47. Aiyegbusi OL, Kyte D, Cockwell P et al. Using Patient-Reported Outcome Measures (PROMs) to promote quality of care and safety in the management of patients with Advanced Chronic Kidney disease (PRO-track project): A mixed-methods project protocol. *BMJ Open* 2017; 7: e016687.
48. Schick-makaroff K, Molzahn AE. Evaluation of real-time use of electronic patient-reported outcome data by nurses with patients in home dialysis clinics. *BMC Health Services Research* 2017; 17: 439.
49. Wong D, Cao S, Ford H et al. Exploring the use of tablet computer-based electronic data capture system to assess patient reported measures among patients with chronic kidney disease: a pilot study. *BMC Nephrology* 2017; 18: 1–10.

Table 1. Participants' characteristics

Characteristic	Number (%)
<i>Patients</i>	
Total N	25
Male gender	14 (56)
Age	
≤ 50 years	6 (24)
51 – 70 years	9 (36)
> 70 years	10 (40)
Treatment modality	
CKD 1-5 ^{a)}	6 (24)
Dialysis	14 (56)
Transplanted	5 (20)
Currently bothered by itch	20 (80)
<i>Healthcare professionals</i>	
Total N	22
Role	
Nephrologist	10 (45)
Renal nurse	12 (55)
Male gender	6 (27)
Years of clinical practice	
≤ 10 years	3 (14)
10 – 20 years	5 (23)
> 20 years	2 (9)
Unknown ^{b)}	12 (55)
Clinical area ^{c)}	
CKD stage 1-5	6 (24)
Dialysis / Transplant	19 (76)

Abbreviations: 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 focusgroups
- c) Sum more than the total N because some healthcare professionals worked in more than one area

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	<p>Patients</p> <p><i>"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."</i> (PCe04, male, 72 years, dialysis)</p> <p>Healthcare professionals</p> <p><i>"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."</i> (CLi01, male, consultant, 23 years clinical experience)</p>
Lack of knowledge on treatment options	<p>Patients</p> <p><i>"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."</i> (PLi06, female, 77 years, CKD 1-5)</p> <p>Healthcare professionals</p> <p><i>"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'."</i> (CLi02, female, consultant, 17 years clinical experience)</p> <p><i>"[My approach to treating itch is] redoubling efforts on dialysis adequacy and phosphate"</i> (CLe04, male, consultant, 15 years of experience)</p>
Attitudes towards the importance of itch as a health issue	
Patients' attitudes	<p>Patients</p> <p><i>"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."</i> (PLi04, female, 69 year, CKD 1-5)</p> <p><i>"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."</i> (PCe13, male, 41 years, transplanted)</p> <p><i>"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."</i> (PLi06, female, 77, CKD 1-5)</p> <p><i>"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."</i> (PCe07, female, 80 years, dialysis)</p> <p>Healthcare professionals</p> <p><i>"I guess if you've got an itch and you can't sleep and you get tired and you get a low mood</i></p>

then in actual fact that is hugely significant really.” (CLe05, male, consultant, 5 years 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 years clinical experience)

Healthcare
professionals’
attitudes

Patients

“I think it’s pretty low down their list of important things [...]. They are extremely busy.” (PCe08, female, 68 years, 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 years, 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, transplanted)

Healthcare 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 years 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 years, CKD1-5)

“They [the renal nurses] always ask about it when I attend the clinic.” (PLi05, female, 72 years, CKD1-5)

Healthcare 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 years clinical experience)

“Itch would be definitely one of my routine questions.” (CMa02, female, consultant, 12 years clinical experience)

Itch as a marker

Healthcare 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 years 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 years 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 years, 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 years, dialysis)

Healthcare 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 years 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 years clinical experience)

Table S1. 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	<p>Patients</p> <p><i>"[During the pre-dialysis meetings] they were discussing...like showing you all the various things [different options of dialysis], but they never discussed itching."</i> (PLi12, male 55, dialysis)</p> <p><i>"I didn't know [itch] had anything to do with the kidneys but I was certainly never told."</i> (PLi08, female, 77 years, CKD1-5)</p> <p>Clinicians</p> <p><i>"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."</i> (CLi02, female, consultant, 17 years clinical experience)</p> <p><i>"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."</i> (CLi01, male, consultant, 14 years clinical experience)</p> <p><i>"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."</i> (CMA02, female, consultant, 12 years clinical experience)</p>
Lack of knowledge on treatment options	<p>Clinicians</p> <p><i>"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."</i> (CMA01, female, consultant, 31 years clinical experience)</p> <p><i>"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."</i> (CLi01, male, consultant, 23 years clinical experience)</p> <p><i>"Antihistamines [...] I don't find that they're necessarily useful."</i> (CMA02, female, consultant, 12 years clinical experience)</p> <p><i>"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"</i> (CMA01, female, consultant, 31 years clinical experience).</p> <p><i>"[Itch] is more important now, now that we know there's something that can be done about it."</i> (nurse, focus group #1)</p>
Attitudes towards importance of itch as a health issue	
Patients' attitudes	<p>Patients</p> <p><i>"[I am embarrassed] because if you're itching and things people think: 'Oh, is he dirty? Has he got scabies?'"</i> (PCe04, male, 72 years, dialysis)</p> <p><i>"[I did not report it because] I thought it was a trivial symptom not worth mentioning."</i> (PLi01, male, 41 years, dialysis)</p> <p><i>"An itch is just an itch."</i> (PCe13, male, 41 years, transplanted)</p> <p><i>"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."</i> (PCe17, male 32 year, transplanted)</p> <p><i>"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'."</i> (PLi05, female, 72 years, CKD1-5)</p> <p>Clinicians</p> <p><i>"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."</i> (nurse, focus group #1)</p> <p><i>"It is important because [...] it is one of the symptoms that impair quality of life of dialysis."</i> (CLi01, male, consultant, 23 years clinical experience)</p> <p><i>"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."</i> (CLe10, male, trainee nephrologist, 4 years clinical experience)</p>

Clinicians' attitudes

Patients

"[The nephrologist] said: 'Well, don't worry about it', and that was his answer." (PLi10, female, 89 years, 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 years, dialysis)

"I think here they care creatinine levels more than itching." (PCe13, male, 41 years, 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 years, 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 years 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 years clinical experience)

"I'm more interested in weight loss, appetite, nausea, vomiting, and other kinds of uraemic symptoms." (CLe02, male, consultant, 14 years 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 years 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 years 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 years clinical experience)

"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 years 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 years 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 years, CKD1-5)

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 years 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 years 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 years 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 years 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 years 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 years 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 years clinical experience)

Itch severity

Patients

[Itch] comes and goes, ehmm, sometimes it is particularly bad, stops you sleeping." (PCe17, male, 32 years, 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 years, CKD1-5)

"The only reason why I got treated is because it was visual, you could visually see the skin was broken." (PCe13, male, 41 years, 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 years, CKD1-5)

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 years clinical experience)