



LIVING WITH CHRONIC KIDNEY DISEASE ASSOCIATED PRURITUS





Introduction

These patients are among the silent sufferers, often hidden from view, who deserve sympathy and a whole lot more. They experience at best severe discomfort, at worst acute pain. They desperately want dedicated treatment. But there is none. So far.

Chronic Kidney Disease associated Pruritus (CKD-aP) is an intractable systemic itch condition that occurs with high frequency and intensity in patients undergoing dialysis. Studies estimate that around 40% of patients with end-stage renal disease experience this moderate to severe itch, with about a quarter reporting severe cases. The majority of dialysis patients (up to 70%) experience it.

Yet CKD-aP remains poorly understood and chronically undertreated. The condition, affecting hundreds of thousands around the globe, is often overlooked by healthcare professionals.

This paper builds on the theme of this year's World Kidney Day, "Living Well with Kidney Disease", and discusses the impact of CKD-aP on the quality of life of patients. It is based on often harrowing interviews conducted by Observia with 75 patients and carers in seven different countries, carried out between December 2020 and February 2021. The debilitating nature of CKD-aP and its severely disruptive effect on their daily lives emerge into the daylight.



1. CKD-aP is distressing

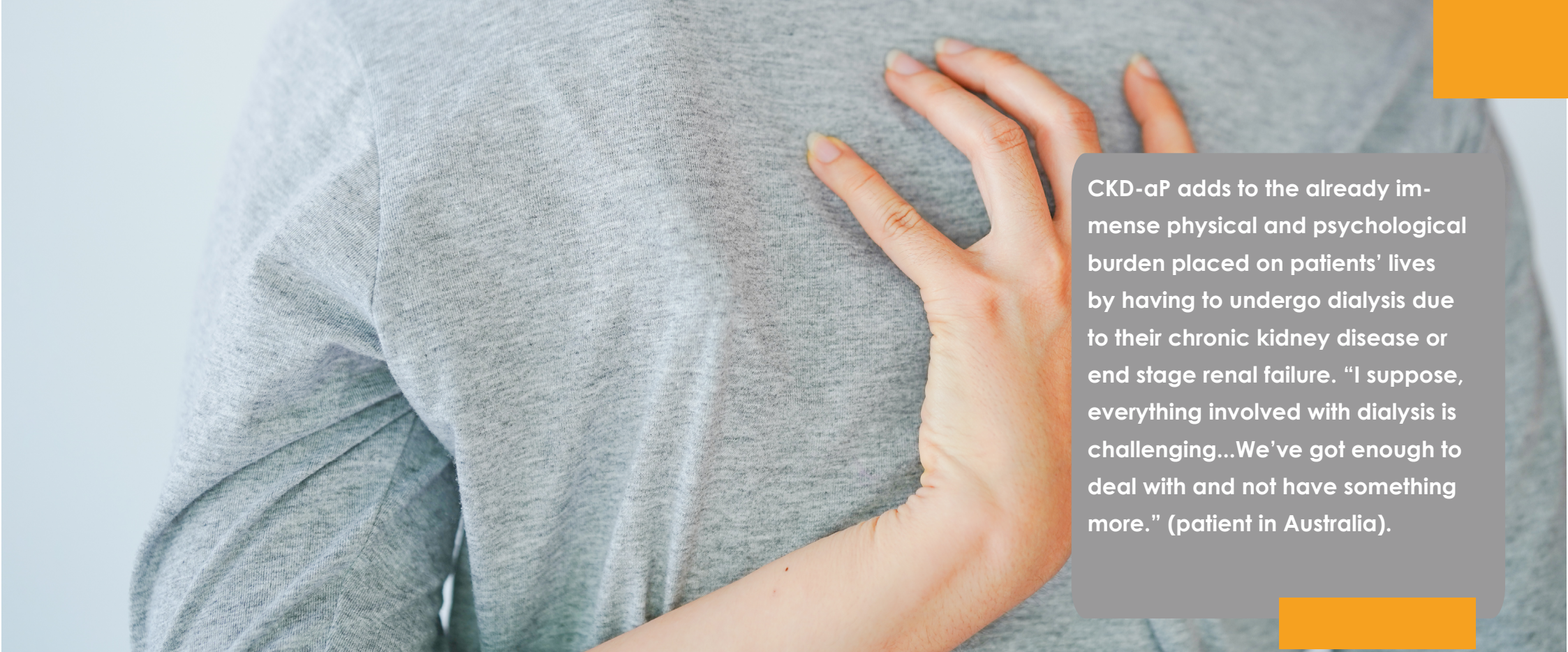
CKD-aP is no simple itch. It can be “unbearable”. It leads patients to scratch themselves until they bleed. They are often forced to treat raw skin that they have scratched. Many patients struggle to live with it.

“Well, it’s quite chronic. It tends to be all over the body, the trunk, back and front, the legs, the arms. Even sometimes my head is all very itchy. Usually when it starts like that it will take two to three days until it dissipates and goes.” - PATIENT IN UK

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CKD-aP has debilitating consequences for patients and appears in different places on the body, some of which can be hard to treat with lotions. Survey respondents describe various levels of severity but one unifying factor among those with mild to severe CKD-aP is that it brings with it an emotional and physical burden. Even those with mild to moderate CKD-aP talk of their condition as one they very much struggle to live with.





CKD-aP adds to the already immense physical and psychological burden placed on patients' lives by having to undergo dialysis due to their chronic kidney disease or end stage renal failure. "I suppose, everything involved with dialysis is challenging...We've got enough to deal with and not have something more." (patient in Australia).

Physically, patients report having to "scratch off my skin because I can hardly bear it. It feels like thousands of tiny fleas working on my skin" (patient in Germany), often resulting in "bad scratch marks on the back [and] arms" (patient in Australia). Some even report that "I need to wake myself up and stop it because it starts to hurt too much. With blood on my fingers. I've scratched all the hair off my left arm and start on my right arm now, and my leg" (patient in Australia).

"half the time you are trying to treat the raw skin that you have been scratching." – PATIENT IN US

Many patients try to distract themselves. But scratching can prove hard to resist. "You try hard not to scratch but you end up scratching in the end regardless" (patient in Germany). "Sometimes I could just literally scratch myself to death, so I've come up with a distraction thing. It doesn't always help..." (patient in Australia).

"it is just so bad that I am scratching till really, I have got no skin left." – PATIENT IN AUSTRALIA

2. It never goes away



Introduction

Some patients report that the itch comes and goes periodically and apparently randomly. This may be in the pre-dialysis phase or during the dialysis phase. However, many feel the itch constantly: it never vanishes, with truly devastating consequences on their lives. As one British patient puts it: "I'm scratching all the time, you can't help it. I can't sleep at night because it's there twenty-four hours a day."

Patients often feel overwhelmed and don't not know how to deal with it – "you get really cranky and it is frustrating, because it is not easy to manage" (patient in Italy). Or: "Still, there are times when my itching feels overpowering, when I say to myself: 'it's really terrible right now' but you just need to hang on." (patient in Germany).

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3. It's ruining my life

CKD-aP can have an enormous impact on patients' quality of life. It may, for instance, affect sleep, socialising with friends, family life or work because it's hard to concentrate. It may even lead to depression. Many even talk of feeling they are losing their minds.

One common effect is sleeplessness. Patients describe waking up during the night or lying restless, trying to resist the temptation to scratch their skin even though they know this will simply make it worse. "The worst time is at night, you wake up with an extreme itch on all parts of your body... it changes from the left arm to the right foot and it really burdens you because there is nothing you can do about it right away." (patient in Germany).

Disturbed sleep can in turn lead to other negative effects such as being in a bad mood, unhappy or depressed: "Often, [it has an impact] on the mood because if you do not sleep during the night, you are less prone to interactions. Sleep is very important" (patient in Italy).

Patients also talk of the impact on their willingness to socialise with friends. A sudden flare up in a public space to the point that it is too distressing to be

amongst other people or be outside. "I have to be honest, when it happens and I'm out, I panic. I walk fast and go somewhere where there are no people, maybe I rest against the wall and scratch" (patient in Italy) – "it's really hard in social situations or if you go out for dinner and you need to excuse yourself. I've been known to go to the bathroom and scratch my arms and legs because it's driving me nuts." (patient in Australia). Patients end up self-isolating, left to cope on their own. As one in Australia puts it: "It's keeping me a bit isolated sometimes."

"Often I am lying awake for nights in a row without being able to sleep." – PATIENT IN GERMANY

**"You don't want to step out. It just does not look right if you are sitting with friends and talking and all of a sudden you are scratching".
– PATIENT IN US**

CKD-aP can prevent patients from carrying out or force them to skip everyday activities. A patient in Italy, for example, says: "Something silly is when I'm at the supermarket shopping and those attacks start, you don't know how to manage them...." Another patient recounted: "Recently, we were on a road trip, travelling by car and I had to pull over, stop the car and scratch myself.."

"In some situations, you are really sick and tired of this itchiness. In the end, we even had to return home, on that trip, there was no point in continuing. My itchiness was just too bad." – PATIENT IN GERMANY

At work, patients may have a hard time concentrating: "... If you're trying to do something and it's itching, you've got to stop what you're doing" (patient in Australia). Some even have to give up their professional activities:

"It has an impact when it's severe, when it's uncomfortable and I cannot pay attention to people as I'm focused on the itchiness which is truly uncomfortable."
– PATIENT IN ITALY



4. I have had to learn to live with my condition

The experience can be so prolonged, with no effective treatment or end in sight, that patients simply become resigned as in: "If I had to choose a word it would be acceptance. It's just something that I have come to accept that it's just going to happen" (patient in US). Or: "I understood that, unfortunately, I have to live with it" (patient in Italy) and "I cannot change anything. A patient on dialysis cannot change anything" (patient in Italy).

Many patients have tried out many different treatments, applied lotion to the skin or talked to nephrologists, dermatologists, GPs, and nurses in order to find a solution for their itching. When none brought the relief that they were seeking, their only option is to accept CKD-aP as "just how it is going to be".

"I'd say it's very annoying, irritating and it has a big impact on my life. It subsides but it never goes away. I just learn to live with it." – PATIENT IN AUSTRALIA

5. What is my condition? It's not been diagnosed



“Well, since I did not know what the causes were – I think I lived with it for a quarter of a year before realising that my kidney disease might be the cause. It took me about three months before I consulted my nephrologist” – PATIENT IN GERMANY

In initial stages of the dialysis process, many patients report not knowing the cause of their itchiness. They also report that they were not aware that the itching is related to chronic kidney disease or end-stage renal failure. So, they fail to consult the relevant healthcare professionals. This bewilderment is often coupled with a feeling of embarrassment, another reason for patients not to raise the issue. In this regard, a patient from Italy suggested to his/her fellows: “I would tell them not to waste time and not to feel embarrassed, and to talk about his issue to the nephrologist or their reference doctor, their pharmacist, their GP... they are all competent people, in order to treat it as soon as possible.”. Unfortunately, this frequently does not happen, particularly with patients who have just been diagnosed with chronic kidney disease.

In addition, healthcare professionals, such as nephrologists, often have not addressed the topic of itchiness when starting dialysis or diagnosing chronic kidney disease, failing to warn their patients that it may appear. So, the issue has to be raised by the patients themselves. A US patient recalls: “Unfortunately, going into dialysis, they didn’t tell me anything about anything. What to expect. How to expect it. Nothing. I learned everything as I went. On the fly.” As a result, it can take patients quite some time before raising this issue with a dialysis healthcare professional.

6. There is an unmet medical need because



Many patients have desperately tried out a variety of treatments to make the itch go away. The most commonly used medications range from antihistamines and phosphorusbinders to a variety of lotions. But many did not work for them: “The doctor started recommending various drugs to me. But the drugs did not help me much, I must say. I was also asked to keep a diary on my itchiness. I did so for a while but that did not help me much either” (patient in Germany).

“I understand that there are different ways to manage it, not stop it” – PATIENT IN ITALY

Treatments may give some relief but only for a short period of time: “First I tried the allergy pills and I had a short term relief, but nothing long term. And then I tried different lotions, where I noticed with some of them after three days, that they don't do anything for me. I don't even know how much money I spent trying to find something that might help” (patient in Germany); “The moisturiser gave me relief but then the itchiness came back” (patient in Italy).

What's more, many patients take prescribed medications that simply temporarily reduce the consequences of the itching: “I used all sort of creams, to reduce the scars” (patient in France). Indeed, the more patients raise the issue, the more they are provided with unsatisfactory treatments. This could range from more/longer dialysis to diet restrictions. Patients can also be burdened with side-effects from treatments, such as drowsiness from antihistamines.

Conclusion



CKD-aP is an unbearable condition to live with, both physically and psychologically. The itch never completely vanishes and damages patients' quality of life. It impacts their sleep, their willingness to interact with people, their powers of concentration. It makes even the simplest everyday tasks hard to carry out. Many patients have given up waiting for a "miracle solution" and have had to learn, however reluctantly, to live with the condition.

Regrettably, healthcare professionals too rarely proactively warn their patients that this condition can arise when dealing with chronic kidney disease. Furthermore, many patients find that the treatments prescribed for the itch provide at best a limited or temporary relief only and consequently try out many different treatments, all of which manage the itch but do not eliminate it.



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