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Experience and impact of crystal pyrophosphate deposition (CPPD) from a patient and caregiver perspective: a qualitative exploration from the OMERACT CPPD Working Group

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Abstract

Objective—To explore the lived experience of people with calcium pyrophosphate deposition (CPPD) disease and the impact of this condition on their daily lives.

Methods—Patients with CPPD and their caregivers were invited to take part in a one-to-one (patient only) or paired (patient and caregiver) semi-structured interview. Interviews covered patients' diagnosis and treatment experiences, and the impact of CPPD on their daily lives. Transcribed interviews were analysed using inductive thematic analysis.

Results—28 patient interviews, six of which included a caregiver, were conducted across five countries. Acute CPP crystal arthritis flares resulted in temporary but profound disability for most patients, disrupting their ability to go about day-to-day activities, and they sought immediate medical attention. CPPD+OA and chronic CPP crystal inflammatory arthritis presented patients with longer term limitations in daily lives. Patients and their caregivers described these disruptions and limitations, which included a reduced ability or inability to complete household and self-care tasks, exercise, socialise, work, and drive. They also described how arthritis pain and resulting limitations adversely impacted upon patients' psychological wellbeing. Delays in referral to specialists and diagnostic uncertainty were described by many. Lack of appropriate treatment or access to treatments only upon worsening of symptoms impacted upon the length of time some patients spent in pain and with functional limitations.

Conclusion—This study is the first to demonstrate the wide-ranging impact of CPPD, and highlights need for improved diagnosis, physician training, as well as greater emphasis upon finding targeted therapies to specifically treat CPPD.

Keywords

OMERACT; CPPD; lived experience; impact; qualitative

Introduction

Calcium pyrophosphate (CPP) deposition (CPPD) disease is a common form of inflammatory arthritis that manifests as acute CPP crystal arthritis (previously called "*pseudogout*"), chronic CPP crystal inflammatory arthritis, and CPPD + osteoarthritis (OA) (1). It affects both appendicular and axial joints. Community-based surveys suggest that it affects 0.42% of the general population, implying a global burden of approximately 30 million affected patients (2, 3). Despite its prevalence, CPPD is an understudied condition with few clinical studies, and, to date – to the best of our knowledge - there have been no qualitative studies of patients' journey from symptom onset to diagnosis, their experience

of receiving treatments for CPPD and of living with the condition. This is particularly important as patients may manifest one or more CPPD phenotypes concurrently, or over time, meaning that their lived experience is varied and may change substantially over time.

Qualitative studies shed light on the experiences of living with a condition that quantitative approaches cannot. They improve healthcare professionals' (HCP) and other stakeholders' understanding of the impact of the disease, thereby promoting patient-centred research (4). Additionally, insight into patients' experiences of pathways to diagnosis and treatment informs ways to improve clinical practice.

This study stems from the work of the Outcome Measures in Rheumatology (OMERACT) (5) CPPD Working Group, established under the OMERACT framework (6) to develop a core set of outcome domains (7, 8) for CPPD using systematic review (9), content analysis of patient, caregiver, HCP and other stakeholder interviews (10), consensus meeting (manuscript under review) and future Delphi exercise. The interviews had the primary objective of providing input on outcome domains reported in previous studies on CPPD. In the absence of evidence on the patient experience of living with CPPD, the interviews also sought to explore and provided a deeper insight of this. The overall purpose of the present study was to explore the lived experience of people with CPPD including symptom onset, initial diagnosis, treatment experience and the impact of CPPD on daily life. In particular, given the diverse clinical features of CPPD, we aimed to explore and describe differences in experiences of its acute and chronic manifestations.

Methods

Participants:

This study included patients with CPPD and their caregivers. The recruitment and sampling procedures have been described previously (10). In brief, five rheumatologists from five sites across the world recruited participants from their own clinical practices. Patient diagnosis was made by clinicians with expertise in the field of CPPD. A maximum variation sampling technique was adopted to ensure the clinical presentations – acute CPP crystal arthritis, chronic CPP crystal inflammatory arthritis and CPPD+OA – were represented and reflected their approximate proportions within the CPPD disease population. Whether participants had axial joint involvement was documented although not sampled for. Patients' caregivers (partner or family member) were invited to participate, as such persons can provide additional insight to the patient experience.

Ethical approval and registration:

The study received ethical approval from West Midlands-Coventry and Warwick Research Ethics Committee, UK (19/WM/0264); Auckland Health Research Ethics Committee (000131) and Auckland District Health Board (A+8575), New Zealand; Partners HealthCare Institutional Review Board (2019P002136), USA; Universitat Autonòma de Barcelona (EC/19/266/5667), Spain; Comitato Etico Indipendente di Area Vasta Emilia Centro della Regione Emilia-Romanga (644/2019/Oss/AOUFe), Italy; and, Lille Catholic Hospitals

Institutional Review Board (CIER-2019-34), France). It was registered on clinicaltrials.gov (NCT04176003) and complies with the Declaration of Helsinki.

Interview procedure:

Participants took part in a one-to-one (patient only) or paired (patient and caregiver) interview after providing written, informed consent. These were conducted between October 2019 and January 2020, face-to-face or by telephone in a private room by a researcher local to each site (KC/CDT/GF/TP/ST) and digitally audio-recorded. Interviews lasted 23 minutes on average, and ranged between 10-50 minutes.

Interview guide:

A semi-structured interview schedule (10) was developed by the multidisciplinary OMERACT CPPD Working Group which includes patient research partners. The schedule was designed with two purposes: (a) to solicit participants' views on potential outcome domains identified in a scoping review (9) for inclusion in a core outcome domain set; and (b) to explore participants' lived experience of CPPD with questions that covered their experience of symptom onset, diagnosis, treatment and the impact of symptoms on their lives. The first purpose formed the scope of the outcome domain generation exercise, utilised a content analysis approach and the findings have been published elsewhere (10).

Data analysis:

Interviews were transcribed verbatim, anonymised and translated into English where required. Data were analysed using inductive thematic analysis, following the steps of Braun and Clarke (11). A sample of interviews transcripts were read independently by two researchers (AF and KC) to identify initial codes, themes and subthemes which described key features of participants' experiences of CPPD. These were discussed to reach consensus on an initial analytical framework. The framework was then applied to and refined following analysis of the remaining transcripts by AF. Throughout the analysis process, a senior member of the research team (AA) was available to review and provide clinical insight to the analytical framework and findings.

Results

In total, 22 one-to-one and six paired interviews were conducted. Participants represented all clinical presentations. Of the 28 patients, 19 (68%) reported more than one clinical presentation: 21 (75%) had acute CPP crystal arthritis, 21 (75%) had CPPD+OA, and 9 (32%) had chronic CPP crystal inflammatory arthritis. All patients with chronic CPP crystal inflammatory arthritis reported at least one other manifestation. Six participants had axial involvement. Patients' characteristics are published elsewhere (10).

Four main themes were identified and interpreted within the data: a) journey to CPPD diagnosis and related experience; b) disruptions and limitations to daily life; c) psychological impact of CPPD disease; and, d) issues in CPPD disease management. Illustrative quotes are provided in tables.

a) Journey to CPPD diagnosis and related experience

Symptom onset and seeking medical attention—Patients and caregivers described an initial set of symptoms consistent with either acute CPP crystal arthritis or CPPD+OA. None of the patients described chronic CPP crystal inflammatory arthritis symptoms at disease onset.

Patients presenting with acute CPP crystal arthritis: A sudden onset of severe joint pain, swelling and an inability to bear weight or to mobilise the affected joint were symptoms which caused the majority of patients to seek medical attention. All those reporting this manifestation on initial presentation sought medical input immediately as the symptoms were abrupt, alarming and left many immobilised (Table 1; a). While some consulted their primary-care physician (PCP) and were referred to a rheumatologist, several sought emergency hospital care due to the pain intensity (1b). Some attending a PCP were referred straight on for hospital inpatient evaluation with concerns their symptoms were due to a life-threatening illness, such as deep vein thrombosis or septic arthritis.

Asymptomatic presentation: One patient recalled cartilage calcification identified by imaging tests undertaken after a motorbike accident, considerable-time before developing acute CPP crystal inflammatory arthritis.

Patients presenting with CPPD+OA: Patients with an insidious onset of symptoms recalled a gradual onset of pain and progressive loss of mobility for which they saw their PCP, and were then referred to a hospital for further investigations (1c).

Time to diagnosis and diagnostic delay—Several patients and caregivers recalled a diagnostic delay, which ranged from a couple of weeks to several years. Reasons for this included PCPs not being able to reach a diagnosis, delays in referral to a rheumatologist, being (mis-)diagnosed with rheumatoid arthritis, gout and even a broken hip, or having multiple tests to exclude other conditions. Some patients and caregivers reported consulting several doctors before CPPD was diagnosed, which resulted in an extended time in hospital and/or in pain (1d). Patients were diagnosed using imaging tests e.g. radiography, ultrasonography or CT scan; or by joint aspiration that revealed synovial fluid CPP crystals. Some patients felt a lack of knowledge of CPPD among non-rheumatologists was a barrier to quicker diagnosis (1e).

Understanding of CPPD causes and beliefs about triggers.—For patients and caregivers, the time of diagnosis was the first they heard of CPPD, where most were told that it occurred due to a build-up of calcium crystals in their joint (1f). Several patients who experienced acute CPP crystal arthritis flares, although told by a doctor during their diagnosis that there were no known triggers for the flares, postulated or believed that certain factors triggered their symptoms. This included genetic factors, other illnesses such as flu, surgery on the affected joint, other arthritic conditions, dehydration and dietary factors (1g). Several patients with other arthritic conditions (e.g. OA) diagnosed prior to CPPD did not fully understand which condition affected which of their joints (1h).

b) Disruptions and limitations to daily life

Patients and caregivers reported that CPPD had wide ranging impacts on patients' lives.

Pain impact—Acute CPP crystal arthritis flares were characterised by sudden episodes of intense, even excruciating, pain lasting a few days to several weeks. This resulted in a short yet substantial disruption to patients' daily life (Table 2; a). For some patients, pain was milder and less disruptive. Patients with chronic CPP crystal inflammatory arthritis described intense, unrelenting, almost unbearable pain (2b). This resulted in a significant longer-term impact as patients were severely limited in daily life, and a reduction in quality of life. Patients with CPPD+OA described a dull, constant ache or pain upon movement of the afflicted joint, ranging in severities, which also resulted in longer-term limitations (2c).

General mobility restriction and adaptation—During flares of acute CPP crystal arthritis, the inability to mobilise the affected joint due to pain resulted in a temporary but profound disability for most patients (2d). Some reported this made it harder to complete tasks (2e) whilst others took bed rest until it resolved. Those with chronic manifestations were limited in the extent they were mobile over a longer period or permanently. This required some to slow down and take extra care, for the others it was a significant disability. Caregivers highlighted how this also restricted how much the patients' got out and about. Some patients with CPPD+OA adapted by using walking aids or had to incorporate additional planning to their day to accommodate joint restrictions (2f).

Ability to perform activities of daily living (ADL) and self-care tasks—During a flare of acute CPP crystal arthritis, many patients were unable to perform ADLs such as housework or shopping. Getting to the toilet or bathing for some was impossible without assistance (2g). Those with CPPD+OA were limited in doing certain ADLs and self-care tasks on a daily basis, depending upon the degree of disability and affected joint(s). Some restricted how much housework they did to avoid consequential joint pain (2h). For those with chronic CPP crystal inflammatory arthritis, ADLs were limited or not possible at all and several required daily support to get washed and dressed (2i). As a result of these restrictions, many participants relied upon a partner or family member for support. Several participants with chronic manifestations no longer lived independently due to their joint symptoms.

Caregivers of patients unable to perform ADLs or self-care tasks reported how they had taken over tasks of daily living and supported patients', either periodically during an acute CPP crystal arthritis flare or permanently due to chronic symptoms. Some patients felt this disrupted their caregivers' lives (2j).

Limiting exercise, social and leisure pursuits—The all-consuming pain and disabling nature of acute CPP crystal arthritis flares and chronic CPP crystal inflammatory arthritis symptoms stopped some patients from partaking in physical activity for the duration of their symptoms. Many with CPPD+OA had changed to low impact activities such as walking and reduced how much exercise they took. Leisure activities requiring the affected joint were limited or no longer possible (2k). Socialising was also paused during an acute

CPP crystal arthritis flare (2l). Although many with CPPD+OA could continue socialising, some reported their pain affected their enjoyment of it.

Disturbed sleep—Several patients and caregivers reported how acute CPP crystal arthritis flares and chronic CPP crystal inflammatory arthritis inflicted pain worsened at night, making it difficult to sleep and eventually being woken-up by the pain (2m).

Ability to work—Some patients, across all manifestations, were unable to complete the requirements of their job and had taken extended sick leave, changed jobs, or taken or considered early retirement. In one case, a patient described how extended sick leave was not granted to them as CPPD was not recognised as a disability by their employer (2n).

Ability to drive—Patients and caregivers reported how an acute CPP crystal arthritis flare or ongoing chronic symptoms, such as an inability to rotate their neck or bend at the knees, made driving difficult or impossible (2o). Caregivers who were reliant on their partner to drive were then limited in getting around.

Clothing restrictions—Joint swelling made wearing certain clothing, footwear and jewellery uncomfortable so patients removed or adapted what they wore (2p).

c) Psychological impact of CPPD disease

The uncertainty and unknown of a flare—Dealing with a sudden, unexplained onset of pain and swelling at first episode of acute CPP crystal arthritis was difficult for some patients. Not knowing what was happening left them feeling anxious and concerned that their life would be very limited. The unpredictability of when another episode could occur was also worrisome for some patients and caregivers (Table 3; a).

Emotional impact of symptoms, disability and limitations on daily life—Patients and caregivers of those who had experienced repeated acute CPP crystal arthritis flares noted how the patients' mood was affected during a flare, and they became very irritable from the pain and the disruption this caused (3b).

Patients and caregivers of those experiencing chronic manifestations also reported how the patients' mental wellbeing was affected due to the frustrations of having to limit their life, from anxiety and fatigue of long, enduring pain and/or from no longer being able to live independently (3c). This was particularly true for those who perceived themselves as being active and for whom socialising was centred on physical pursuits. In one case, a caregiver reported how their partner expressed thoughts of suicidal ideation during an extended period of unrelenting and intense pain (3d), leaving the caregiver feeling helpless until a suitable treatment was found.

Acceptance of symptoms—For some patients and caregivers, symptoms of CPPD were attributed to an expected decline of mobility with old age and patients were not psychologically affected by having to slow down or limit themselves (3e).

Connection with gout—A couple of patients expressed dislike at the connection of the term *pseudogout* with gout, due to its nomenclature, and, were embarrassed by the negative connotations attached to the term ‘gout’ (3f).

d) Issues in CPPD disease management

Experience of currently available treatments—While some found currently available treatments for acute CPP crystal arthritis to be effective and acceptable, many experienced side effects, had other medical conditions which contraindicated certain drugs or found treatment effects were short-lived (Table 4; a). Patients with mild symptoms did not consider the lack of suitable treatment options to be of great importance. Some patients and caregivers of those with chronic CPP crystal inflammatory arthritis with superimposed flares of acute CPP crystal arthritis reported how patients received several different treatments in trial and error, before finding one that worked. This resulted in an extended time in pain and suffering (4b). Patients with mild persistent symptoms of CPPD+OA as their sole presentation received the same set of treatments as those with OA, e.g. adhoc over the counter painkillers, steroid injections, arthroscopy, while those with severe symptoms received additional treatments such as magnesium, hydroxychloroquine, colchicine, vitamin D, and opioids.

For both patients and caregivers, pain was considered the key aspect of CPPD they wished to be addressed by an effective treatment, as this would enable life to be continued as before (4c). However, many patients did not like having to take medication(s), particularly pain-relieving medication, on a regular basis regardless of how effective they were (4d). Some patients with CPPD+OA manifestation had been told surgery was a treatment option, however, hoped to avoid it until their symptoms substantially worsened (4e).

Accessing treatments—For those without a defined treatment plan to relieve or prevent flares, access to treatment at the onset of acute CPP crystal arthritis flares or worsening of chronic CPP crystal inflammatory arthritis symptoms was often delayed until they could get a PCP or hospital appointment. As a result, some attended hospital emergency rooms for pain relief on more than one occasion or were left to endure the pain (4f).

Clarity of CPPD disease management and prognosis—After experiencing an acute CPP crystal arthritis flare, one patient felt there was a lack of clarity on how their CPPD would be managed in the future (4g). Several were left with unanswered questions about long-term prognosis such as the risk of permanent disability or developing other arthritic conditions (4h).

Discussion

This is the first study to explore the experience of people living with CPPD disease. The findings show that CPPD disease has a profound impact on patients’ daily lives, principally caused by pain and immobility which affects numerous aspects of activity, participation, productivity and emotional wellbeing. Acute CPP crystal arthritis flares result in temporary but disruptive periods of disability, and CPPD+OA and/or chronic CPP crystal inflammatory symptoms result in longer-term limitations. The findings also highlight current issues in

CPPD diagnosis and management, including diagnostic delays and lack of appropriate treatments, which impacted upon the length of time some spent in pain and with functional limitations.

To our knowledge, the nature of CPPD disease's impact on patients' psychological well-being and quality of life has not been described elsewhere, however, there are considerable parities with similar conditions. In a qualitative meta-synthesis of the patient experience of a gout flare, participants described flares as a disabling period during which they were unable to walk, grip, exercise, complete self-care tasks and household chores, drive, participate in social activities, complete the requirements of their jobs and wear certain footwear or clothing, and had difficulty sleeping (12). These all bear resemblance to the impact of an acute CPP crystal arthritis flare as described by participants of this study. The meta-synthesis also showed that flares affected intimacy and relationships, which was not found in the current study and warrants further investigation given the importance of this to patients with gout and the similarities to an acute CPP crystal arthritis flare. Compared to gout, people with CPPD are typically older (13) and so loss of work productivity may not be as common a burden among CPPD patients with only a few participants reporting this, however, it was a considerable impact for those who did. Participants with chronic manifestations of CPPD, particularly CPPD+OA, similarly reported long-term limitations on activity, participation, emotional wellbeing and loss of independence comparable to people with knee OA (14).

Although individual CPPD clinical presentations have similar impacts to other common rheumatic conditions, many patients have more than one clinical presentation and so will experience a multitude of burdens. For example, both long-term limitations in activity as well as short-term periods of disability were reported by many participants.

Similar to gout and OA, pain was a central feature for participants which had not only a physical but psychological dimension (15). Worry at the intensity of unexplained pain at symptom onset and over the uncertainty of future flares, as well as irritability during flares have also been reported by patients with gout (16, 17). Feeling mentally drained and frustrated by persistent, untreated pain and the inability to participate in normal daily activities among participants with chronic presentations is also shared by with those with OA (14) and repeated gout flares (12, 15). A recent qualitative study with psoriatic arthritis patients similarly found that long diagnostic delays and a subsequent worsening of untreated symptoms has an immense psychological toll on patients, with some expressing suicidal ideation (18). Recent research has also shown an association between frequency of gout flares and depression (19, 20). This highlights a need for further research to assess the psychological impacts of CPPD to better understand its effect upon patients and how to support their emotional wellbeing.

Given the disruptive impact acute CPP flares have on patients' lives, priority should be given to treating and preventing acute CPP crystal arthritis flares. As highlighted in the findings, effective therapies are needed for chronic manifestations of CPPD particularly given that currently available medications to reduce pain and inflammation do not work for the majority of patients and are often contraindicated in elderly persons.

Additionally, there is a need to minimise the diagnostic delay. Issues highlighted by participants suggest that physician-related factors such as misdiagnosis, insufficient CPPD knowledge among primary care and non-specialist secondary care doctors and delays in referral to specialist care contributed to this. This has similarly been seen elsewhere, although patient-related factors such as delay in initial help-seeking are also an important contributor to diagnostic delay in other rheumatic conditions (16, 18, 21-23). Further research should look in more detail at the factors affecting diagnostic delay, but findings suggest that improving CPPD knowledge among non-specialist doctors including general practitioners and emergency room staff from whom patients typically first seek medical advice may be an important step in more timely diagnosis.

Given the lack of clarity some patients had of their diagnosis, association with other conditions, flare triggers and prognosis, patient health literacy could also be improved at the point of diagnosis. Greater clarity of CPPD diagnosis and information on prognosis could also help patients feel more in control and better equipped to cope with the uncertainties of this disease. This is especially true for patients with acute CPP crystal inflammatory arthritis. For instance, when patients with this manifestation were told that there are no known triggers of acute CPP crystal arthritis, they postulated and held onto their own beliefs.

Strengths of this study include that participants represent the different clinical presentations of CPPD and were from several countries across Europe, North America and Australasia, increasing the generalisability of our findings. The primary analyst was a non-rheumatologist and so was able to approach analysis without preconceptions, minimising bias in data interpretation. The involvement of a second coder (KC) and CPPD clinical expert (AA) then enhanced the rigour of the analysis process and credibility of our findings. Limitations include that patients were recruited from rheumatology clinics so there is possible selection bias towards patients engaged with the healthcare system as well as those with more severe disease presentations. As interviews were conducted concurrently across different countries, experiences raised by a participant at one research site may not have been followed up at others, and so the findings may downplay the extent or importance of certain experiences.

In conclusion, this study for the first time demonstrates the physical and psychological impacts of CPPD, and highlights a need for improved diagnosis, patient and physician education, as well as greater emphasis upon finding targeted therapies to treat CPPD.

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Highlights

- Acute CPP crystal arthritis flares cause profound temporary disability including inability to self-care.
- Chronic CPP crystal inflammatory arthritis and CPPD with concomitant osteoarthritis results in long-term persistent limitations.
- Delays in referral to a specialist and initial misdiagnosis contribute to diagnostic delay.

Table 1.

Journey to CPPD diagnosis and related experience

a.	*It's frightening just that the onset was so quick. It just was like, "Okay, who drove a nail into my knee overnight?" type of thing. It was extremely painful.* BOS005, acute CPP
b.	*I was sitting at home, and the pain was just getting so bad that we decided to go into the emergency room*. BOS002, acute CPP
c.	*I experienced the inability to extend my arms straight, and my elbows weren't extending completely. And I suddenly realised I'm unable to touch my finger on my shoulders, which is a normal sort of thing you can do… it just seemed a bit unusual. So I mentioned it to my doctor.* AUC001, CPPD+OA
d.	*It was a long hospitalization and it was extensive. CPPD was the final diagnosis but mostly as of exclusion 'cause they thought I had all sorts of medical conditions*. BOS001, CPPD+OA
e.	*At the beginning [note: approximately ten years ago] the diagnosis was different. They used to tell it was one thing, then a different one…When the x-rays showed calcium lines, they started to identify the problem. But it seems to be poorly known. Not all doctors knew about it, it depended who, they said one thing or a different. Three or four years ago they defined clearly as chondrocalcinosis*. BAR001, acute CPP
f.	*Dr XXX at the rheumatology department of the XXXX Hospital suggested that I should have some x-rays done of my elbows, which I did, which showed quite a lot of calcium build up in my elbow joint. And at that stage that was the first time I'd ever heard of CPPD and the symptoms*. AUC001, CPPD+OA
g.	*[Referring to acute CPP episodes] I, it's funny though, too much of a particular food I think causes it.* AUC004, acute CPP and CPPD+OA
h.	*I've never known which part of my problem is the pseudogout and which part is the osteoarthritis. I've always assumed that the pain was just the osteoarthritis, and the swelling was the pseudogout, but I have no idea how to tease the two apart.* BOS003, acute CPP and CPPD+OA

Table 2.

Disruptions and limitations to daily life

a.	*I just woke up, and I couldn't really walk properly… It was stabbing pain. It was like nothing I've ever really experienced… it was out of nowhere*. BOS003, acute CPP
b.	*It was unbearable… the pain was extremely intense… It was something exaggerated. I felt there was something scratching inside my body*. BAR005, acute CPP and chronic CPP
c.	*It's more of a nuisance than a searing pain. I get by, but it's just a nuisance 'cause it's there all the time, and it certainly restricts my movement*. AUC001, CPPD+OA
d.	*The problem is that it is almost completely disabling. I can't walk*. BAR002, acute CPP and CPPD+OA
e.	*I only needed to put more effort. Because, normally, I can do everything better and easier. But with a flare, it gets more complicated. I mean you still do it, but differently*. BAR006, acute CPP and CPPD+OA
f.	*It impacts on the way you think about doing things. So like I'd rather sit in the front seat of a car because I can put my feet out straight. Whereas if I have to sit for a long period of time with the knees bent, yeah it gets quite sore. So you're just thinking oh well where am I gonna sit*. AUC009, CPPD+OA
g.	*I couldn't get to the toilet*. AUC005, acute CPP, chronic CPP and CPPD+OA
h.	*I guess I don't do, I choose not to do things that I otherwise would do, like the home handyman sort of stuff that I would do at home if I was 100 percent*. AUC001, CPPD+OA
i.	*Husband: She can't wash herself, she can't cook, etc. It has an impact on her surroundings*. LIL006, acute CPP and chronic CPP
j.	*This impacts also my relatives' life. They have to plan everything (holidays, work transfers etc.) so that someone is always near to me, in case of need*. FER004, CPPD+OA
k.	*I was in the habit of going on long hikes. That has all stopped*. LIL002, acute CPP and CPPD+OA
l.	*It also affects my family and friends. I don't feel like going out or doing anything, my mind is only focused on the pain*. BAR002, Acute CPP
m.	*I am in pain all day… even more in the night… I can't sleep anymore*. LIL004, acute CPP, chronic CPP and CPPD+OA
n.	*Well, I would say that since it is rare, not everyone is trained to understand it. In one occasion, I requested a sick leave but they denied it. There wasn't a document stating my diagnosis. They said arthritis was not a disease that caused permanent disability*. BAR001, acute CPP
o.	*I cannot drive my car, I try to keep the legs extended*. FER002, acute CPP and CPPD+OA
p.	*When it affects my ankle, my foot, I have to wear open shoes. I can't stand normal shoes. My foot swells, so I can't use them*. BAR001, acute CPP

Table 3.

Psychological impact of CPPD disease

a.	*It's the psychological fear of a flare that bothers me*. BOS003, acute CPP and CPPD+OA
b.	*When flares happen, then I get very moody because I can't do what I had planned with my family, or my job, or hobbies, whatever. Flares ruin every plan. I can't walk, so I am not able to enjoy anything. That is very annoying.* BAR002, acute CPP
c.	*When you are in pain all the time you are worn down by it and it is complicated to manage. I feel diminished by it because sometimes I am not able to be independent and so psychologically it is upsetting.* LIL005, chronic CPP and CPPD+OA
d.	*Caregiver: It was a torture to look at him complaining every day. He used to say "I want to jump from the balcony, I want to die", the pain was too intense. Looking at him without knowing what to do or how to help him.* BAR005, acute CPP and chronic CPP
e.	*Yeah, but you take these things, you think of these things as old age. You don't think of them as a disease.* AUC005, acute CPP, chronic CPP and CPPD+OA
f.	*I recall a cartoon with a man with his foot up, all bandaged, and it's the result of overeating. I wouldn't want to tell anybody I had pseudogout, because they think, "Oh, gout."* BOS004, acute CPP

Table 4.

Issues in CPPD disease management

a.	*At first it was still ok when I had the injections, it's true that at first it calmed me down and I was pleased that everything was better, I barely had any pain. But then after a short-ish time it suddenly came back and it was worse, far, far worse.* LIL004, acute CPP, chronic CPP and CPPD+OA
b.	*I went to the doctor and [they] prescribed me different pills to alleviate the symptoms, but no result. I was taking corticosteroids, high doses, 40mg I think, also methotrexate and acfol. They only controlled the pain briefly, but I was still suffering many flares.* BAR005, acute CPP and chronic CPP
c.	*The pain. Because once the pain does go then, yeah, you know, everything's back to normal.* AUC002, acute CPP and CPPD+OA
d.	*The use of analgesics, well, it is a pain to have to keep on taking them.* LIL006, acute CPP and chronic CPP
e.	*The fact that I will need to have surgery in my knees scares me a lot, the surgery room also. I would consider surgery only if I couldn't walk anymore.* FER005, acute CPP and CPPD+OA
f.	*While I was waiting to go to the doctor, sometimes up to a week because I did not have an appointment or whatever, the pain did not cease. Sometimes the pain and swelling were so intense that I had to go, even if it was admitted through the emergency room. In one or few days I can't move if I don't take the medication immediately. When I wait without having the meds, the pain becomes unbearable.* BAR001, acute CPP
g.	*To me there isn't a plan here and saying, you know this is, this is what we will follow up, or we will do. That sort of, that's what I can't see there.* AUC010, acute CPP
h.	*I suppose you ask the question, because you've got the calcium crystals and that, does it lead to another arthritis?* AUC010, acute CPP