

Table S1. Codes and Quotes Emerging From Social Work and Occupational Therapy Interviews
Persistent Pain
<i>"There's joint pain as well. There's all kinds of pains. There's sharp pains. There's achy pain in the bone. And of course, the arthritis pain and then nerve pain from the impingements ... I have relatively mild bone pain. ... I know a lot of people have 'broken bone' pain all the time. It's hard when you've never had normal-feeling bone."</i>
<i>"... while they're calcifying, it hurts like the very devil."</i>
<i>"'Oh, you're fat, you're overweight, get up and exercise,' but they didn't understand that the pain ... I couldn't. There were days where my mom would have to lift my legs up out of the car, to get in and out of the car or to go up and down a step."</i>
<i>"Well, I have a lot of bone pain. The bone spurs in my ankles, a lot of back pain from arthritis ... I know a good part of that is losing weight. I am struggling with doing that, but I am moving in that direction slowly."</i>
<i>"The pain measurement scales are worthless. It's hard to explain to someone who hasn't lived with pain their whole lives that my 4 or 5 is probably their 7 or 8. But I'm so used to it I just don't pay attention to it until it gets to extreme levels."</i>
<i>"I was screened for a clinical trial ... and the doctor called me up and said, 'why didn't you tell me you broke your arm?' and I said, 'I didn't know I had.' I thought it was my normal bone pain ... it wasn't any different from the kind of pain I was used to."</i>
<i>"I knew I had to choose a desk job ... not [be] an athlete."</i>
<i>"I had to medically retire ... I built transmission parts. Oh my gosh I loved it."</i>
<i>"I live in pain 24/7. I was on anti-inflammatories until recently. I'm in real pain now, because I had to go off of them. ... I've been through the whole pain clinic thing. There's nothing really that they can do, short of giving me opiates."</i>
<i>"I went to a pain clinic, and they tried different things and I finally decided that ... enough is enough, that I was going through this sort of cyclical thing ... oh, this is going to work, this is going to work, oh, it doesn't work. I can deal with the pain better than the ups and downs of the hope and the disappointment."</i>
<i>"I've resisted [opiates] because if I'm going to be dysfunctional, what's the point?"</i>
<i>"I take an [NSAID] and I keep my joints warm."</i>
<i>"I felt very guilty, and to this day I feel guilty, but I had to weigh the difference between having a wonderful child and not having a child at all."</i>
<i>"I never have a great day. I have OK days ... I've got bad days. ... There's days where I really, really force myself through the pain, because I don't want to miss out on my [kid]."</i>
Fear of Falling
<i>"I (slowly) became terrified of falling."</i>
<i>"I don't like open spaces ... (or) crowds ... I'm afraid of getting knocked down."</i>
<i>"I just don't like the big open areas with all the people running around ... a lot of times I panic. I will look for a wall next to me or somebody with me just to feel safer."</i>
<i>"As long as I'm standing by the bench, I can still play catch with [my son]. It's not bad, but if I try standing in an open area, then it's worse."</i>
<i>"I'm afraid of falling, but it's not an irrational fear."</i>
<i>"Even if I'm walking in a parking lot somewhere and I hear a car horn beep, I'm jumping and I'm looking. I'm afraid something's going to happen. But from a doctor ... 'oh, you've just got to get it in your mind, just concentrate and focus, just get out and just do it.' But they probably didn't understand if I jump and fall the wrong way, my leg could break again."</i>
Lack of Credence
<i>"I'm nervous about going to a physical therapist or a personal trainer, because I do have such major spinal issues."</i>
<i>"... most doctors don't know that there is such a thing as bone pain in the absence of trauma. I don't think they're prepared for ... if the material of the bone is defective ... there's pain there, too."</i>
<i>"There is only so much time in a visit ... they [doctors] will say 'where does it hurt?' I'll say 'pick a joint. Everything hurts.' ... You have to go with the one that hurts the most at the time. Otherwise, people get overwhelmed."</i>
<i>"A lot of patients learn to not say anything to the doctors. I don't think I mentioned my foot calcifying for like 5 or 10 years because there's nothing to do ... or then they come back and say nothing's wrong ... so you get kind of trained ... to not give the full picture."</i>
<i>"You have a problem with this shoulder and you make an appointment with the doctor, and it takes three months to get in to see him. When you get there, shoulder's fine but the knee is hurting. And then that's like classic drug-seeking behavior, you know?"</i>
<i>"... nobody believed me ... (I was) treated like I was drug-seeking."</i>
<i>"I think it was a CT ... a 3D image of my spine ... it was really cool to see that there was a little stalactite in my spinal column and that explained the pain. Because you know we are at risk of being told we're imagining this stuff. So, to be able to see it truly was reassuring."</i>
Resilience and Compensation
<i>"We all have a similar personality and that is a little bit aggressive. It is part of what we have to be, to be able to endure all the things we physically have to endure."</i>
<i>"To me it's a way of life. I've adjusted what I do and how I live to just get by every day."</i>
<i>"I think the XLH community are the kings of compensators; we compensate constantly for what we can't do. It's just second nature."</i>
CT, computed tomography; NSAID, nonsteroidal anti-inflammatory drug; XLH, X-linked hypophosphatemia.