

Table SII. Selected quotes for "attack impacts" and "caregiver impacts"

Theme	Example quotation
<i>Attack impacts</i>	
Pain and/or swelling	"This can range from a swelling on the arm or the leg, which can be rather uncomfortable, to a swelling in the stomach, which really makes me so ill that I cannot move." "[Attacks] in the face, then better to not go out because you look like a monster."
Asphyxiation	"I had a violent attack and had to be tracheostomized in the hospital".
Unable to perform daily activities	"I feel like if my hand gets swollen, that day is controlled by that attack. It affects setting the table, cleaning, doing small things that you can't do with the swollen hand. So you can't do much until the swelling goes away."
Bedridden	"My life is very problematic at the moment. I more or less have weekly attacks, my attacks are rather severe, so I need to stay in bed and can't get up for 2 days."
Need to cancel plans	"And it was usually when you were looking forward to something – Christmas or a birthday – then you often got an attack. There you were – and had to say that you couldn't participate."
Unable to travel	"[The attack] prevented me from driving, so I couldn't travel where I wanted to."
Decreased productivity	"There is an effect on my work life, because I sometimes have to cancel job appointments when I have an attack." "I am on these business trips so often. There were situations when I had to leave the road to get to a parking area to inject myself, and this is not funny at all." "When I worked in a clothing store, if I my hand got swollen, there were many jobs there that I couldn't do, like put the prices on things with the little price gun, bag things."
Absenteeism	"About once in 3 months I am sick-listed for a few days." "In my work I have times when I am very busy, I can't stop working, and if I have an attack at one of these times it is a big problem...if I'm not available I could lose my job and it would affect everyone. You have to plan who can cover for you in the best manner. In fact, I have everything prepared to be able to work from home, from the hospital, with the technology we have now..."
Anxiety	"During the attacks I'm usually distressed, very nervous. I mean, I know perfectly what is going on and the consequences, but it's like I'm tense. I'm tense waiting for the consequences, in a way." "It can be inside the throat. Then I am afraid that I won't be able to breathe."
<i>Attack modifiers</i>	
Availability of hereditary angioedema treatment for acute attacks, pre-procedural prevention, and long-term prophylaxis	"Before, we didn't have this medicine and so I had more anxiety, with the worry of travelling in an airplane or of travelling and having an attack when you're there – what will you do in a country where you don't know the language? So it was worse, much more anxiety. If you have the medicine in your suitcase, then you can just administer it yourself or leave it in the hotel and everything is ok. Having access to this medication lowers my anxiety a lot." "When I go to the dentist now have to get an IV placed just in case, which is an inconvenience. But I welcome this discomfort if it avoids others. I had a colonoscopy, and they gave me an injection prophylactically to prevent inflammation." "Last time [I had an attack] I already knew I would get [long-term prophylaxis injection] soon, so this helped to relax me. In other situations, I wasn't relieved so much after an attack had passed because I knew there would surely be the next attack soon."
Patient education and ability to self-administer acute medication	"Before learning how to self-administer the medicine, I was a slave to the disease. I cried a lot and was very depressed. I felt very vulnerable...Having the doors opened to being able to learn to self-administer the medicine has improved my quality of life because now I have control." "My boyfriend has been trained how to inject me, should there be an emergency, so generally I feel safer."
<i>Attack-related resource use</i>	
Acute medication use	"During this last attack, I felt so sick when I woke up and went straight to vomit in the bathroom and thought I had to get my medicine right away. So I had to find a way to find my vein and inject myself."
Treatment visits	"I was given medication at the emergency room – I have an arrangement with the emergency room at [Hospital]. If I have an attack, then I can go there for treatment. As a rule there is someone there who knows who I am – there she is again. And then I get my treatment and can leave again."
<i>Caregiver impacts</i>	
Missed leisure time	"I can only sit down in my chair and just stare. And then my wife has to do all the work at home on her own, because I don't take my share."