

Table SIII. Selected quotes for "long-term impacts"

Theme	Example quotation
<i>Psychosocial impacts</i>	
Anxiety about passing hereditary angioedema to children	"I had wanted to have more children, but for me, it was very important to consider the 50% chance of transmitting this to a child....I love children and would have liked to have had many more, but it was too risky.... My spouse and I separated 3 years ago. In a way, HAE also influenced the separation. We separated in part because he wanted to have children and I did not."
Anxiety about future attacks Worry	"My life has changed in the sense that one lives perpetually worried about when an attack is going to occur." "Because of having so many episodes, my mind isn't free, it's always thinking. Because of this, it's prevented me from doing many more activities. I'm so worried about my illness that I can't think of anything else. Stressed. It's a continual and permanent stress. I'm not ever able to be at peace."
Stress driven by uncertainty	"It's the uncertainty that goes along with it. When there is a tiny little mark somewhere. How is going to develop? Will I have to go to hospital or will it just go over? Or is it just a totally normal swelling? It's just the uncertainty and insecurity."
Inability to plan/travel	"Although I have my medicine, when I plan trips, I'm always afraid. I try to lesson that fear, but I always have it when I have to travel outside of [City]. So it affects mostly my ability to plan."
Social/ relationship impairment due to difficulty making/keeping plans	"I can't keep up with others, need to go home earlier from events or from work in the past....I only have very few friends left, because I have always been sick when they had a party or other event."
Inconvenience due to need to transport medication in a cooler	"I didn't do any travelling unless I could get the medication in less than half an hour. And that is a major drag. We like to travel to different countries, and now I always have to carry the drug around in a cooler on battery power."
Limit exercising/playing sports	"I used to enjoy playing ball in the team, but I can't do this anymore because I would be missing a lot of training or match hours." "I have to be careful when playing badminton that the racket isn't in the same place all the time. I cannot just go out for a run with a friend as I would like to. I cannot play handball or soccer either. My activities are very limited."
Absenteeism	"There have been a few occasions when I could not go to work because I needed to have an examination in [City]."
Decreased productivity	"In the workplace, well it's like you're stagnating... When I go to work I want to 'eat the world' because I don't know if it'll happen tomorrow, if tomorrow I'm going to be able to perform my work....The truth is that yes, I do feel that I am at a disadvantage at work, because when you're going to continually perform an activity, you don't want to lose the thread, you could say, right? And when you don't go one day, it's like you lose a little of the thread."
Limited career choices	"I tried to be an airline stewardess but I had to let that idea go because I was afraid I could have an attack while on a flight. So it has even affected my choice of career."
Unable to advance	"Having so many sick days and days where I cannot do my job 100%...I have the feeling that this [has a bearing on my chances for advancement]."
Loss of employment	"I know that my employment is supposed to be terminated because of my disease; this is emotionally stressful for me because I do not know what will happen then. The Office for Integration of the Handicapped tries to help me in this, but the situation is still unsure." "In my previous training I had to stay home sick a lot, but my colleagues/trainers did not understand this at all, they told me I wasn't 'suitable for the German job market'."
Difficulty explaining condition to boss and co-workers and lack of understanding	"My colleagues have hinted sometimes, I think, that they believe this is just rubbish. Because they cannot look into my stomach when I get ill and have to go home. I have the feeling they don't quite believe that this is real. I sometimes feel that people think about me in a way they shouldn't."
<i>Long-term resource use</i>	
Medication use for long-term prophylaxis	"I take [medication] daily. It is supposed to reduce the outbreaks, to have as few as possible. One time, when I reduced the dose a little, they were more frequent. I've taken it for 3 and a half years." "Now I use [medication] twice a week prophylactically, and in case of an attack I inject another dose."
Routine care visits	"Once a year I am in [City] for treatment/examination, and for this I have to take a day off."
Mental healthcare	"Before I started self-administering the medicine, I had anxiety attacks and even had to go to the psychiatrist because this disease gave me anxiety."
<i>Side effects of oral long-term prophylaxis therapy</i>	
	"The side effects were stomach upsets and stomach cramps. So I thought, 'this is not a good idea.'" "[Oral prophylaxis medication] was a catastrophe. I got this when I was 17. My periods stopped, I developed muscles like a heavyweight champion, I was aggressive, I was moody, suicidal. The worst thing a young person can experience. The frequency of the attacks while I was on [medication] was as high as if I had taken no medication, even though I used a high dosage."