

Table SII. Example of extracts randomly selected by the researcher from the pool of narratives written by the patients in reference to their personal experience

It was as if...	I thought it was...
<p>"...my skin was no longer mine"</p> <p>"...I was being stung by pins all over my body"</p> <p>"... lichens sneaked under the sheets and walked over me"</p> <p>"... having fire under the skin"</p>	<p>"...I didn't give it much thought and that it would have gone away"</p> <p>"...caused by stress or by the herpes simplex virus or chicken pox contracted in 1972"</p> <p>"I thought they were simple micro insect bites"</p> <p>"...wheat allergy, and I was going crazy because I cannot live without bread"</p> <p>"...a common allergy and finding the allergen would have solved the problem."</p>
<p>At the diagnosis I felt..</p> <p>"...a bit confused, worried in a way, and perhaps relieved to have learned what I had to fight against"</p> <p>"When they told me I had chronic hives, I felt like dying. I was desperate because I did not, and still cannot accept this thing ... I hope that urticaria will not last lifelong."</p> <p>"...miserable, because I was told that there was no specific treatment"</p> <p>"I had looked on the internet and I had already realized..."</p>	<p>To understand the disease...</p> <p>"I did the allergy tests for contact, for food, drugs, etc. ..."</p> <p>"To understand the causes I underwent several tests. Especially for allergies, but also tests for lupus, rheumatoid factor ... even an orthopantomogram ... But all this didn't lead to anything; we didn't understand what had triggered all this. I just know that I had an autoimmune disease ... but with no explainable causes ..."</p> <p>"I read a lot and I did all the possible tests, but unfortunately no-one can understand what this is caused by"</p>
<p>Doctor-patient relationship</p> <p>"My doctor tended to give me few answers so I changed doctor"</p> <p>"At the beginning the therapy seemed to work, but the doctor did not satisfy me, he was very concise in his explanations and easily dismissed me, without even fixing the next appointment."</p> <p>"The only time I got angry was when the doctors told me that the hives could derive from stress, because in my opinion it was a diagnosis they formulated whenever they did not know what to say. Or when they told me that it could be caused by a number of things, which in most cases, are unknown"</p> <p>"He was the first doctor to give me satisfaction. He made it clear that it is almost impossible to heal, that my case is very complicated, because it is not a regular hives, but perennial. He does not deceive me but keeps me updated and often goes to conferences to seek breakthroughs. He has become part of the family."</p>	
<p>The pathway of care</p> <p>"Looking back on the path to this day, I see a lot of theories, a number of ideas, a plethora of hypotheses ... but also a lot of checks, withdrawals, examinations ... sometimes I even wondered if I went in the 'right places'..."</p> <p>"If I look back and I think about the fatigue, the pain, the money spent and no results achieved, I feel defeated, a loser."</p> <p>"I feel tired and I find it absurd that a remedy for a disease so stupid cannot be found."</p> <p>"Looking back on the path to this day, I know that urticaria is the terror of allergists because it is difficult to find the cause. "If he had visited me from the beginning, I would have avoided a year of stress associated with urticaria."</p>	<p>The therapies</p> <p>"I would definitely eliminate unnecessary antihistamines and lead a much more peaceful life."</p> <p>"When I found out that there are no cures, beyond continuous antihistamines, I felt like choking."</p> <p>"Despite everything it is tough; I have a bag full of medicines from which I never separate myself."</p> <p>"After the initial shock I began a cycle of visits and efforts to care especially with glucocorticoids that led inevitably to a state of discomfort that went beyond the disease."</p> <p>"With immunosuppressants I felt better, I was able to stop taking glucocorticoids."</p> <p>"For 6 months I took cyclosporine, but I did not see any results, because I still had to take glucocorticoids for the entire period."</p> <p>"Diet required too much sacrifice, I cannot afford to eat out."</p>
<p>Family relationship</p> <p>"I am pampered and protected by my family."</p> <p>"My family has been understanding, especially considering that at first I had become irritable, depressed, and concerned - going from moments of decline alternated to moments of improvement in which I was hoping that the disease was over."</p> <p>"They were worried, because this thing stresses me greatly and makes my life miserable."</p> <p>"My loved ones were astonished every day by the sudden and abundant eruptions"</p> <p>"None of my family members has given importance to my disease."</p> <p>"My urticaria was considered by the family as if it were a deadly disease, and this has only made things worse."</p>	<p>Relationship with "others"</p> <p>"With others, I have no problem except that sometimes they see me with red signs because I scratched myself."</p> <p>"With others, I try to joke about it, using a bit of irony. Better not to complain, it doesn't help anyone and you become a whiner ..."</p> <p>"With others, I have never had any problems ... when my face is swollen I look like the rough copy of someone with a bad plastic surgery ... but I laugh about it, of course."</p> <p>"I speak about my illness and I try to explain what it is; also in the attempt of removing any fears about it being contagious."</p> <p>"Sometimes it was difficult, I had to postpone evenings out with friends or other people whenever the hives were visible, or invent the excuse I had a toothache just to avoid having to give explanations I could not give."</p> <p>"I was afraid that others could see me with wheals."</p>
<p>At work...</p> <p>"I could not go to work and perform my job (masseur) because I felt I needed to scratch myself all the time, but I could not take my hands off the body ... I was desperate."</p> <p>"I had many problems on the job, because my colleagues and bosses did not believe it is a crippling disease."</p> <p>"I was often absent from work, because of the wheals on my face or on my limbs, which prevented me from walking."</p> <p>"At work it was much better, but the stress was increasing."</p> <p>"At work, I am understood and treated as a normal person."</p> <p>"I have no particular problems at work ... perhaps because now my colleagues know about it. If someday I have bumps on the hands or on the face ... they just ask me" how I feel."</p>	

Table SII contd.

Today life with urticaria is...	For the future...
"It has become a habit even if the discomfort is often unbearable."	"Tomorrow is a" question mark ". I never know when these symptoms will occur."
"Living with urticaria is a habit, as well as taking the medication, so I'll go ahead."	"I see the future with things being the same as they are now, or maybe worse, I sincerely do not know what to expect."
"Today life with urticaria is awful, it's giving me a nervous breakdown."	"When I think about the future, I hope I will be healed one day, without needing to take so many medications."
"Today life with urticaria is devastating."	"Thinking about the future, I hope that my urticaria will go away just the way it came. You never know what the future holds!"
"Currently life with urticaria is difficult, burdensome, driving me insane, and debilitating."	"I would like an easier diagnosis."
"My life with urticaria is quite easy."	"I would like urticaria to become easy to cure, just like the flu."
"Today life with urticaria is quite simple. I've learned what to do when the hives show up and the situation is precipitating. I take my medications and go forward."	"I would like urticaria to also be handled in the outpatient clinic, and with natural therapies."
"Today I can live with urticaria as long as I take my therapy to attenuate the symptoms."	"A journey faster than the one that I went through."
The experience of writing	
"First, someone is reading my story, secondly I hope that these stories will be a starting point to help people like me with this damn problem."	
"Fine and confident, hoping to be helpful for a project that perhaps will change something for the better."	
"I am heartened by the fact that this condition is taken into account, given that the National Health System does not recognize it as a disease."	
"I want to thank you, because for the first time I was able to express what I feel, in the hope someone will understand me ... listen to me ... hoping that my experience, even if negative, will help collect useful information; I admit this experience helped me too, as it encouraged me to write things that I had never said before. I feel better, relieved. Thank you for the work you do and I hope that the research will bear fruits. It's hard to believe but I have to hope. Thank you again for this opportunity."	
"Thinking about urticaria upsets me a little, as much as talking about it."	
"I felt miserable and uncomfortable. I made myself uncomfortable. Although my brain already knew the story, recalling information had a certain effect on me... Sometimes the brain needs to really hear oneself talk."	

The table is divided based on the prompts provided in the semi-structured storyboard. Texts were originally in Italian and were analysed by Italian researchers from a semantic perspective applied to the Italian language. (Note: For the purpose of accurate reporting, texts are herein have been translated into English with a special effort to maintain the meaning as close as possible to the original, both from a linguistic and cultural point of view).