

# Patients with systemic lupus erythematosus and their experience with vaccination against COVID-19: a descriptive and explanatory study

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Dear Editor,  
The coronavirus disease 2019 (COVID-19) pandemic contributes to the burden of living with systemic lupus erythematosus (SLE). We previously described the experiences and perspectives of Italian SLE patients during the COVID-19 emergency, showing as the unexpected arrival of the COVID-19 emergency broke a balance, with loss of health status control, anxiety and stress (1). The rapid development of vaccines against SARS-CoV-2 has led to uncertainties in patients affected by autoimmune diseases: an online survey reported an acceptance to receive vaccine in 54.9% of patients (2).

We conducted a descriptive and explanatory study to describe the expectations and potential concerns related to COVID-19 vaccination in SLE patients, by using a narrative approach and thus providing the patients' perspectives. Thirty-one patients [M/F 29/2; mean age 45.2 years (SD 8.9 years)] were enrolled at the time of first vaccination dose. Participants filled out an anonymous self-administered web-based questionnaire consisting of four questions regarding their experience with SLE over the past year and with vaccination (Table I). The *Positive and Negative Affect Schedule* (PANAS) (3) and the *Generic Risk Perception* (GRP) (4) were administered in all patients.

The synthesis of the answers and their categorization is summarized in Table 1. The

experience during the last year was described with a predominantly negative connotation, referring to the fear to contract the virus. Concerning the question on vaccination, people basically answered in two ways, referring either to the fear or concern related to the risk to their health and possible side effects, or to the feeling of relief, opportunity/freedom/health protection and gratitude for having received the vaccine.

When asked to describe the day of vaccination, most patients described an emotional state (anxiety, tension; agitation; confidence; quietness; excited), or mentioned aspects related to the context, such as the organization of the vaccination center. Other people engaged in the description of the contextual/organizational aspects, mostly attributing a positive connotation to the event.

The application of the PANAS questionnaire referring to the period before and after vaccination demonstrated a significant improvement in the majority of investigated positive items and the reduction of the negative ones (Figure 1). Finally, a substantial change in risk perception was observed: the proportion of patients perceiving high risk of being infected with SARS-CoV-2 decreased from 29.4% to 2.9% (Figure 2). Our study has some limitations, in particular the use of a web-based anonymous survey and the limited number of enrolled subjects. In conclusion, our descriptive and explanatory study indicates that CO-

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**Table 1** - Categories of the answers to the open-ended questions.

Type of categorization	Answer categorization	N (%)	Example of quotation
<b>Question 1</b> <i>How have you experienced your condition as a Lupus patient this past year?</i>			
Direction	Negative/ trending to negative	16 (51.6)	"Not very well"; "Poorly, I limited my outings as much as possible, and I did not work"
	Neutral	8 (25.8)	"Normally"; "trying to respect the rules"
	Positive/ trending to positive	7 (22.6)	"Well"; "in a quiet manner"
Content	Experiences/emotions experienced during the year	22 (71.0)	"Well"; "normally"; "with more concern, with a great sense of fragility and vulnerability"
	Behaviors/attitudes during the year (staying at home, respecting the rules)	9 (29.0)	"Trying to respect the rules"; "trying to avoid gatherings, staying home most of the time and having little contact with other people"
<b>Question 2</b> <i>How did you feel when you were called for the vaccination? What did it mean to you to be called for the vaccination?</i>			
Content	Relief, health care opportunities, happiness	25 (80.6)	"Overjoyed and relieved to finally get vaccinated"
	Risk-related fear or concern	6 (19.4)	"Fear for possible side effects, since I felt fine at the moment"
<b>Question 3</b> <i>Describe the day of vaccination</i>			
Content	Experiences/emotions experienced	18 (58.1)	"Waiting half an hour before leaving the vaccination site was a long wait. During those minutes that never went by I had the perception that there might be a problem due to the vaccination. But it was just my anxiety"
	Contextual aspects	13 (41.9)	"I went to the Institute with my mother (also suffering from autoimmune disease) and with great kindness they welcomed us for acceptance, we did not wait and after the administration of the vaccine we stayed 15 min for any side effects. Verified the absence of the latter we went away"
<b>Question 4</b> <i>Do you think anything will change in your life now that you have been vaccinated? (If so, what)?</i>			
Content	"Yes, it will change something"	16 (51.6)	"Yes completely, anemically more than anything else. I have to say that feeling privileged and grateful were the feelings that characterized these long post-vaccination phases the most"
	"Nothing will change"	8 (25.8)	"I will continue as before with the right precautions I do not feel safe being vaccinated indeed perhaps some fear in more"
	"Not much will change"	4 (12.9)	"For the moment I think it will change little, I continue to observe the same rules of distancing"
	"I don't know"	3 (9.7)	"I don't know"

COVID-19 vaccination substantially changed the perspective of SLE patients, with a positive direction towards the future.

**Conflict of interest**

The authors declare no potential conflict of interest.

**Acknowledgments**

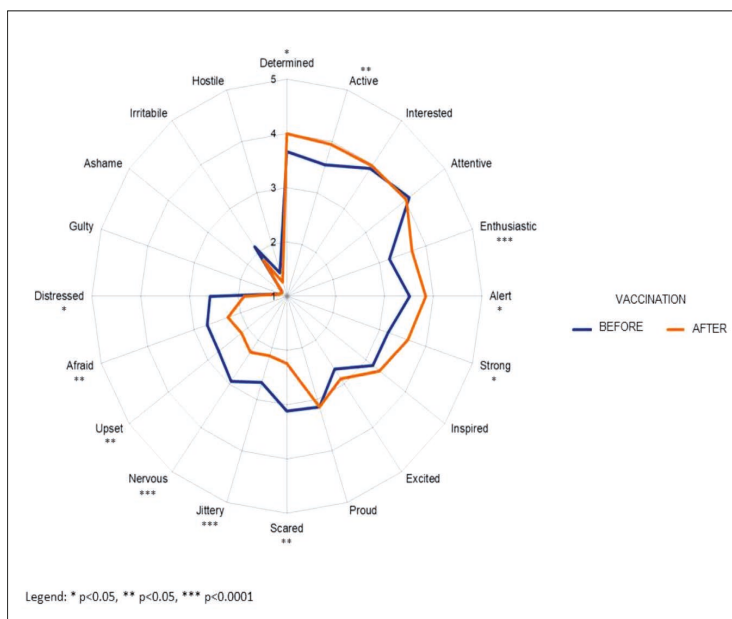
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**Contributions**

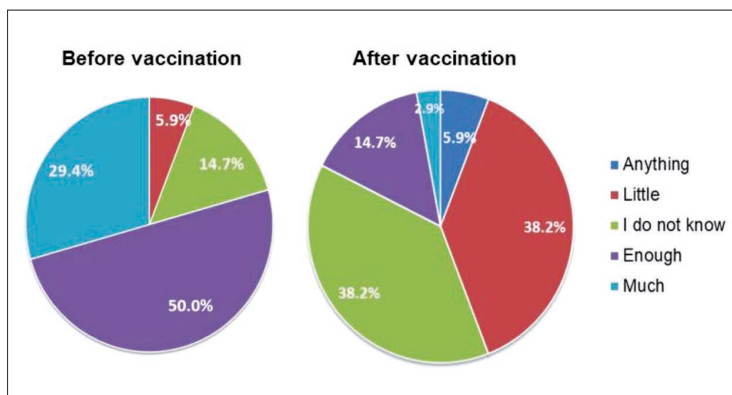
All authors contributed to the study conception and design. Data collection was made by GO, FN and CA; data preparation and analysis were performed by FC1, VC and FC2; the first draft of the manuscript was written by FC1, VC and FC2; all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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**Figure 1** - Results related to PANAS questionnaire referring to the period before and after vaccination.



**Figure 2** - Data about the Generic Risk Perception (“To what extent do you perceive the risk of being infected with SARS-CoV-2 before and after the vaccination?”).