

Patient-doctor communication gap
What are my key concerns when I am having a lupus flare
Results of a speed-shop at Lupus2022 meetings

Background

The Patient – Doctor communication gap is often discussed. As part of the SL Euro lupus 2022 congress a joint workshop was run between patients and care givers, physicians, healthcare professionals and industry representatives to discuss around the theme of “lupus flare”, with the aim to highlight different points of view and discuss about possible explanation of discordance. The results of this speed-shop could represent a starting point for futures work and understanding on this topic.

Method

As part of the SL Euro lupus 2022 congress a “speed-workshop” was held, taking the opportunity of having different stakeholders attending the same session on lupus measurement tools. A total of 57 persons participated. Participants were asked first to complete, in writing, the statement “ For me, a lupus flare is when I / my patient.... », based on their “real life experience” of what would make them identify an even as a lupus flare and not on standard book definitions of flares. In a second step, participants were asked to identify their “key concerns when facing a lupus flare”, and rate them as huge, big, or medium/small by placing them on different flipcharts. Answers were written on post-its of different colours per type of participants, forcing short answers focusing on key aspects to facilitate the analysis and the grouping of the answers. The post-its were then analysed and classified to identify commonalities and discrepancies.

Findings

“Recognition” of a flare

A total of 57 statements were collected, of which 22 from patients, 16 from doctors, 12 from industry and 7 others (carers, HCP). Their wording was evaluated for reference to externally assessable (visible / measurable) items, or to specific symptoms of features. The same grid was used for the 4 groups statements. The answers are summarized in Table 1.

Table 1: flare definition by group

" recognition of a flare"				
	patients	doctors	industry	others
	n=22	n=16	n=12	n=7
reference to:				
Measurable or visible factors	8 (36.4)	14 (87.5)	5 (41.7)	3 (42.9)
• Including – fever	5 (22.7)	0 (0.0)	0 (0.0)	1 (14.3)
Felt Non visible symptom	20 (90.9)	2 (12.5)	1 (8.3)	6 (85.7)
• of which: fatigue	13 (59.1)	4 (25.0)	1 (8.3)	3 (42.9)
• of which : pain	11 (50.0)	3 (18.8)	1 (8.3)	3 (42.9)
• of which : other	8 (36.4)	5 (31.3)	2 (16.7)	2 (28.6)
ability to function	2 (9.1)	3 (18.8)	1 (8.3)	1 (14.3)
New or relapsed symptom	4 (18.2)	4 (25.0)	3 (25.0)	0 (0.0)
need for more meds	0 (0.0)	2 (12.5)	3 (25.0)	0 (0.0)

Out of 22 patients, only 8 (36.4%) have associated the concept of flare to a specific symptom, notably fever. In the majority of cases, patients definition of flare was based on less measurable symptoms such as increased fatigue (13 – 59.1%) and pain (11 – 50%); in particular they do not refer to inflammatory manifestations. As an example, joint manifestations are reported as pain and not as swelling of joints. Interestingly 4 (18.2%) patients define a flare as the recurrence of clinical manifestations or the appearance of new symptoms.

By contrast, out of 16 doctor answers, 14 (87.5%) were considering objectively assessable factors to define a flare. In the 2 remaining cases a flare was defined as “the need for more steroids”, and “ the patient not being able to conduct his/her normal activities due to pain, fatigue”, in this latter case with a vision similar to what reported by patients and mainly based on the impact of the flare on how the patient feels and function.

Industry answers were mixed, as far the other participants are concerned (health care professionals and care givers) the answers were closer to the patients perceptions.

Key concerns when facing a lupus flare

A total of 93 items were collected from the above participants, of which 50 from patients and 26 from Doctors. These items could be classified in 4 key groups : concerns around daily life & logistics; overall anxiety; symptoms and medication.

Table 2 provides the summary of concerns types raised by each group

Table 2: concerns related with flares

	PATIENTS				DOCTORS			
	Total	Huge	Big	Mid	Total	Huge	Big	Mid
Daily life/logistics	16	9	4	3	2	1	1	0
anxiety	16	5	7	4	5	1	2	2
symptoms	15	7	5	3	13	10	3	0
medication	6	5	1	0	8	3	4	1
total	53	26	17	10	28	15	10	3

Anxiety and daily life & logistics were the most common patients concerns and mentioned by the 72% of them. In these the daily life & logistics concerns appear to have a bigger weight, with more than half being “huge” concerns. In is very important to observe that this concern appears to be less important for doctors (2/26)

These concerns appear less important for physicians, as they rate symptoms and medications as most important concerns when a patient is flaring.

From this analysis, it appears that when doctors face a flare they focus mainly on “protecting the body” with huge concerns on symptoms and possible aggravation, while the patient confronted to a flare has broader concerns referring particularly “how will I handle my daily life and “is this disease even going to leave me in peace”.

Discussion

The communication difficulty between patents and doctors starts from the very feeling of what a flare is. 91% of patients include in their recognition of a flare a factor that cannot be “easily” objectivated by a doctor. For 59.1%, it is fatigue, for 50% pain. Only 36% of patients include an externally visible factor, most often fever, which might, or not, be attributable to SLE. In contrast, 88% of doctors will require an externally visible/measurable factor to “identify” a flare. These 2 different starting points can create a first communication gap, as well as a difference in the qualification of an event as a flare or not.

The patient-doctor communication is also not helped as each group has very different preoccupations when confronted to an event considered as a flare. In fact while patients have a perspective focusing on the impact of flares on their daily life and logistics (35% of huge concerns, 30% of all concerns), and face anxiety over disease/life in the future (30% of all concerns 19% Of huge concerns), the doctor's focus is on symptoms (67% of huge concerns, 46% of all concerns) and medications (29% of all concerns), with only 7% of the doctors focusing on the patients "immediate" daily life/logistics issues, and 18% on anxiety (but interestingly mostly as a medium/small concern). While these different dynamics are perfectly logical and fitting each individual's role in the relationship, with the doctor's primarily and rightly focused on the disease, and the patient on "how to live with it", identifying ways to better include this gap in the patient-doctor dialog might help enhance the relationship and in turn improve treatment adherence or minimising patient anxiety.

Conclusion:

The different perceptions of what is a lupus flare, and the concerns that come top of mind for patients and doctors respectively when the disease manifests itself, provide compelling examples of the challenges in patient doctor communication. Increased awareness of these differences and how to deal with them is critical to improve patient and doctors joint working in the fight for the disease.