

The communication GAP between patients and clinicians and the importance of patient reported outcomes in Systemic Lupus Erythematosus

Elena Elefante^a, Alain Cornet^b, Jeanette Andersen^b, Amy Somers^b, Marta Mosca^{a,*}

^a Rheumatology Unit, Department of Clinical and Experimental Medicine, Azienda Ospedaliero-Universitaria Pisana, Italy

^b Lupus Europe, Brussels, Belgium

ARTICLE INFO

Keywords:

Systemic Lupus Erythematosus
Patient-reported outcomes
Patient-clinician communication gap
Health-related quality of life

ABSTRACT

Systemic Lupus Erythematosus (SLE) imposes a great burden on the lives of patients. Patients' and physicians' concerns about the disease diverge considerably. Physicians focus on controlling disease activity to prevent damage accrual, while patients focus on symptoms that impact on Health-Related Quality of Life (HRQoL). We explored the physicians' and patients' perspective and the potential role of Patient Reported Outcomes (PROs). Physicians are aware of the theoretical usefulness of PROs to collect information deriving from the patients' perspective. However, they often do not know how to interpret and use these questionnaires in a real shared therapeutic strategy.

For the patients, it's important to be seen as a whole person with a true consideration of how they feel and function. Strategies to help bridge the communication gap could include: better use of time during visits, preparing for the consultation, a more understandable lay language used by the doctor, a dedicated nurse.

Systemic Lupus Erythematosus (SLE) is a chronic inflammatory systemic disease characterized by multi-organ involvement and a complex clinical picture, with a wide range of manifestations of varying severity and an unpredictable relapsing and remitting course [1,2]. Due to its complexity and heterogeneity, SLE is not a single-target disease, and many aspects must be taken into consideration in the management of the disease: controlling disease activity, preventing damage accrual, minimizing treatment-related toxicities, and improving patients' quality of life (QoL).

Since when the principle of "treat to target" (T2T) has been applied in SLE [3], many efforts have been made to define targets in SLE. Over the last few years, the DORIS definition of remission [4,5] and the LLDAS definition of Lupus Low Disease Activity [6] have emerged as the most meaningful treatment targets, after multiple validation studies in large independent cohorts.

The physicians' view on lupus dominated the development of remission criteria and it was postulated that a control of disease activity would improve QoL in SLE, although the definitions of remission and LLDAS do not address Health-Related Quality of Life (HRQoL) or disease burden.

While some studies have demonstrated an association between a stable condition of remission or LLDAS and better HRQoL in SLE patients, this may sometimes prove to be a weak association [7].

The disease imposes a great burden on patient's lives and 35–50% of patients with SLE perceive their health as "fair/not so good" or

* Corresponding author. Rheumatology Unit, Department of Clinical and Experimental Medicine, University of Pisa, Via Roma 67, Pisa, Italy.
E-mail address: marta.mosca@unipi.it (M. Mosca).

“poor”. Living with SLE is difficult; as patients will have to face phases of activity of the disease, accept long term therapies, make compromises with side effects and accept the risk of potential risks related with therapies to treat their condition. The long term effects of this chronic disease mean that patients will likely have to cope with fatigue, pain and limitations of their daily life activities, at work as well as in the family [8–11].

In this review, we tried to provide an overview of current literature data on factors that influence patient-physician communication and to summarize the two different perspectives on the management of the disease. Notably, the paragraph on the patient’s point of view on the communication gap is the result of a focus group on this topic among SLE patients.

1. Patient-physician discordance and communication gap in SLE

It is evident from the literature that the disease outcomes that are important to the physician do not completely correspond to those that are important to the patient. The doctor is mainly focused on preventing organ damage, while the patient gives more importance to symptoms that have a greater impact on daily life. In the literature, this is referred to as “discordance”, a term that implies that doctor and patient evaluate the disease differently but that there is not a right or a wrong view [12].

Several studies have explored which are the main determinants of this gap between patients and physicians in SLE. In a multi-ethnic cohort of 300 subjects with SLE, a discrepancy in the evaluation of disease activity between doctors and patients was found in 58% of patients and in most of these cases disease activity assessed by the patient was greater than that assessed by the doctor. In particular, it emerged that clinicians gave more importance to alterations in laboratory tests, while patients evaluated the activity of their disease mainly in relation to joint pain and perception of their degree of functioning [12]. Similarly, Yen et al. found that the strongest predictor of discordance between doctors and patients was physical pain, followed by components related to skin and kidney manifestations of SLAM [13]. In a recent Italian monocentric study, among patients in LLDAS, the majority (73%) was discordant with the rheumatologist’s evaluation, judging their disease as active (according to the SLAQ score). The authors found that factors associated with patient-physician discordance among patients in LLDAS were past and ongoing joint involvement, a concomitant diagnosis of fibromyalgia and ongoing glucocorticoid treatment, even at a low dosage [14].

Overall, these data highlight, on the one hand, the patients’ lack of understanding of the real meaning of some laboratory alterations and clinical manifestations, which should be better explained; on the other hand, physicians’ limited ability to grasp the aspects of HRQoL that are most significant for the patient [15].

In an interesting study by Golder et al., doctors and patients with SLE in Australia were asked to declare their degree of concern about questions relating to QoL and questions relating to disease activity and damage. The patients’ main concerns were found to be related to aspects of HRQoL, such as fatigue and degree of functioning; conversely, doctors said they were more concerned about the manifestations related to organ damage. Furthermore, the three main concerns reported by patients (all related to functioning) were not routinely assessed by most physicians in clinical practice [16].

Fatigue and chronic pain represent two of the most pervasive and bothersome symptoms for patients with SLE, influencing patient perception of disease status, and often represent the most important treatment goals from the patient’s point of view [17–20].

This has been confirmed in a recent work done in the framework of the European Reference Network (ERN) ReCONNET in which existing clinical practice guidelines on SLE have been reviewed, aiming to outline the state of the art and to identify current unmet needs: the persistence of symptoms like pain and fatigue, even when remission of SLE disease activity has been achieved, has emerged as an unmet need from the patients’ perspective [21].

It appears evident, in the management of complex diseases like SLE, that treatment decisions are driven by a “hierarchy of evidence” dominated by clinician judgement that do not always reflect the patients’ condition [22]. Physicians tend to consider symptoms like generalized pain, fatigue and depression as unrelated to SLE, not addressing them well during clinical evaluation.

In an attempt to overcome this communication gap, Pisetsky et al. proposed a model that posits that manifestations of SLE can be divided into 2 categories, type 1, and type 2. Type 1 manifestations include the classic signs and symptoms of SLE that are clearly correlated to the proinflammatory mechanisms (e.g., nephritis, arthritis, and vasculitis) and that are typically assessed in measures of disease activity, such as the SLE Disease Activity Index (SLEDAI). Type 2 manifestations include symptoms such as fatigue, widespread body pain, depression, anxiety, cognitive dysfunction, and sleep disturbance that are often unrelated to periods of disease activity as conventionally defined, and usually do not respond to therapy with immunosuppression or corticosteroids. Type 2 symptoms can dominate in PROs because of their effects on HRQoL. According to the model, the type 1 and type 2 categories are not mutually exclusive. The attribution of symptoms of type 2 to SLE is difficult because the underlying pathophysiology is not entirely understood and the overlap with typical manifestations of fibromyalgia is evident to the point that the authors proposed to use the 2016 ACR criteria for fibromyalgia as a self-reported survey to assess features of type 2 SLE. However, the authors believe that the incorporation of type 2 symptoms into the framework of lupus may have positive clinical implications. It might improve patient-physician interactions by validating patient concerns and acknowledging type 2 symptoms as an important component of SLE; improve patient understanding of disease symptoms; enhance the priority placed on the evaluation and treatment of these symptoms [23,24].

The existence of a communication gap between patients and physicians carries clinical significance. It can negatively affect patient care; compliance with treatment, good lifestyle options to adopt and long-term outcomes of the disease [25]. Conversely, a better interaction between patients and rheumatologists has proven to be linked to better outcomes, such as QoL, medication adherence, fewer side effects and lower disease activity and organ damage [26]. In a recent study by Sloan and co-workers, who interviewed patients with lupus, improving QoL was the most frequently cited reason for medication adherence, whereas preventing organ damage and/or death was only cited by <10% of participants. Moreover, the role of medical relationships in medication adherence emerged: supportiveness of the current medical relationship was, in fact, directly cited by a quarter of participants as a reason for adhering [22].

So, the patient-doctor communication gap is often reflected in the high prevalence of concerns from patients that they are not listened to, not considered as a whole person or that the doctor is treating something that is not their key problem. The doctor does not use a holistic approach to care.

As emerged in a recent systematic literature review on physician-patient communication in rheumatology, two elements appear important for maintaining a good relationship between the two parts: patient participation in the medical consultation and trust in the physician [26].

2. The physician's point of view

From the physician's point of view, evaluation of disease activity still represents the key point in the assessment of SLE patients in routine clinical practice and it is a target for all therapeutic strategies [27,28], as high or persistent disease activity is associated with poorer outcomes [29].

Since the T2T approach has been applied to SLE, growing evidence from the literature show that reaching the targets of remission and LLDAS as soon as possible during the disease course, is linked to better outcomes in SLE in terms of damage accrual, glucocorticoids withdrawal [30] reduced cardiovascular risk [31] and improved mortality [32]. In this context, physicians have guidelines to follow and clearly feel the responsibility for favoring choices in the management of the disease that ensure better long-term outcomes [22], changing in this way the natural course of the disease.

However, disease activity and/or organ damage are not strongly associated with measures of QoL. Optimizing therapeutic strategies, over the last decades, has allowed an improvement of prognosis of SLE patients, but this has not been paralleled by an improvement of patients' HRQoL; which is defined as one of the treatment goals in the 2019 EULAR recommendations for the management of SLE. Our actual recommendations do not only call for T2T; shared decision-making (SDM) is also endorsed in the overarching principals. SDM is more than explaining what needs to be done, it requires the inclusion of QoL and the burden of lupus into the process of deciding a strategy [33].

2.1. But do we really know how to do that?

There is a greater awareness of the need to have a holistic view of the patient with SLE [34] and of the difficulty for the physicians to collect information deriving from the patients' perspective. Consequently, Patient Reported Outcomes (PROs) are acquiring an important role in the management of SLE, as a potential tool to overcome the communication gap between patients and clinicians.

PROs are health status evaluations directly reported by the patient without interpretation by a physician or anyone else [35]. Physician-assessed health outcomes and patient-reported outcomes capture unique and complementary information.

In clinical trials, the target response is mostly defined by changes in disease activity instruments, while PROs were never used as the primary endpoint. The results of PROs collected mainly in clinical trials and real-life studies of belimumab show that, although patients' QoL improved over time (particularly in the physical domains), biological therapies were insufficient to induce normalization of PROs (as defined by age- and sex-matched general population) [36].

In the more recent studies on Anifrolumab in SLE, patients treated with Anifrolumab (particularly those with high Interferon signature), compared to placebo, showed a trend in functional improvement, as demonstrated by an improvement in the FACIT-F scale for fatigue and in the physical and mental component summary scores of the SF-36 [37–39].

As stated above, clinically relevant treatment targets, from the physician's perspective, are those associated with an improvement of long-term outcomes for patients. From this point of view, available data on the association between patient reported HRQoL and long-term outcomes in SLE are still scarce and conflicting. Recently, Azizoddin et al. demonstrated that the Physical Functioning domain of SF-36 was significantly and independently predictive of an increased risk of mortality in a large SLE cohort [40]. Moreover, Lindblom et al. performed a post-hoc analysis of data from the BLISS-52 and BLISS-76 open-label extension studies: they found an association between EQ-5D Full Health State experience at the beginning of open-label phase and reduced subsequent organ damage accrual, over the course of up to 8 years of follow-up of SLE patients receiving add-on belimumab [41].

Despite recognising the importance of PROs in theoretical terms as tools for understanding the patient's viewpoint, physicians bring several explanations for not systematically using them and not considering their results.

Within the Integrate project (<https://www.integrate-sle.eu/>), a European founded project undertaken by the Rheumatology Unit of Pisa, the Scuola Superiore Sant'Anna of Pisa and the Rheumatology Unit of Dusseldorf, patients and clinicians were called to work side by side in the development of a new strategy for the monitoring and treatment of SLE, relying on the integration of patient-driven data to the traditional clinical evaluation. On-line surveys were completed by European experts in the field and patients. The main topics from these surveys were then discussed into dedicated focus groups of patients and clinicians. The role of PROs in the management of the disease was the subject of much debate among clinicians. The main obstacle to the use of PROs from the physicians' point of view was lack of time during outpatient evaluations. Therefore, physicians suggested that some strategies should be put in place to optimize the use of time during visits, e.g., PROs to be filled in at home or in the waiting room before the visit, or an electronic diary to record clinical and lifestyle data from their daily routine.

Other reasons given for not using PROs were the lack of validated questionnaires, the subjective nature of some measures (e.g., of fatigue and pain), which give poor credibility of the results according to the clinicians, and discordance with the rheumatologist's own interpretation of the patient's condition. Most clinicians declared that they find it difficult to interpret and use the results of these questionnaires. Several clinicians expressed the view that PROs were drivers for change in treatment only when the patient was in remission or when disease activity was low. There was general agreement that PROs could be especially useful when tracked over time,

when the patient is followed-up by the same doctor or the same team of rheumatologists (data not published).

A patient's perspective is still not accepted as equivalent to the physician's perspective in treatment decisions [42]. Some physicians fear looking at the patient's perspective, because of uncertainties of how to face it and then treat it [43].

During focus groups within the Integrate project, clinicians also discussed how possible it is to actively involve patients in their treatment, sharing therapeutic strategies and allowing them to "self-manage" some aspects of the disease itself. They all agreed that educating the patient on the disease, therapies, and lifestyle choices was a necessary condition for them to play an active role in the management of the disease. When patients are well-informed about the disease, it is then possible to delegate some "basic" tasks and engage them in the management of their disease (data not published).

3. The patient's point of view

Patient - doctor communication has undoubtedly improved over the past 25 years but remains one of the most important issues highlighted by lupus patients.

In its most severe (but unfortunately still frequent) form, the patient feels considered as "the sum of biologic parameters" with no true consideration for the way they feel or function. This is unlikely to change, unless these patient-reported events can be measured with validated statistics and treated with approved lupus related guidelines. As a patient expressed, "What is not measurable or treatable does not exist and is not discussed in the consultation".

Most situations are however not that extreme, and the patient-doctor communication will take other forms, depending on the barrier or discordance at the origin of the gap.

3.1. Before even the consultation starts...

Time is the most frequently identified cause of the patient-doctor communication gap. The time constraints create a shadow on communication well before the visit. Patients know that time will be short, even when the doctor does their best to be available. Due to its many different expressions, there is a lot more to discuss in lupus than for a simple cold. For lupus patients, many symptoms can be potential expressions of "lupus being back". It takes time to establish a relationship and be ready to discuss sensitive issues. It takes time to understand what each component of the treatment is used for and it takes time to be reassured about new or recurring symptoms. Patients know and understand that doctors have limited time assigned to each of them, while some will react by not discussing some of their concerns to respect the doctor's schedule (possibly at the price of not disclosing important information), others will enter the appointment with the big hope that it will answer the 15 different points on their list. Yet, even in limited time, all feel the need to be heard, listened to, considered, and examined. They await the doctor's verbal or body language confirmation that they heard the fatigue they faced and the reassurance that the doctor touched their joints or checked something on their skin to validate or invalidate symptoms of possible concerns. Patients often have a list of questions in their minds, half of which they will forget to ask and half they will hope to be asked; "What other question did you have for me?". Time spent with eyes on the computer is not viewed as consultation time.

A second big challenge in communication is the increased occurrence of "changing doctors". In some countries, the system does not allow patients to benefit from an assigned doctor who will always follow them. In other situations, schedules are managed with some (needed) level of flexibility resulting in frequent changes. For lupus patients, the personal relationship built with "their" doctor is key. Having a new doctor carries the need to make sure that they have all the facts about their history, to restart explaining everything "from scratch" or they will have doubts on the conclusions. "It takes more than the full consultation time just to say everything important that is in my file ... and then we can only start getting to know the new doctor". In some situations, an additional frustration is created when the patients discover last minute, at the consultation, that it is not their usual doctor that will see them. This brings an additional level of stress, a real obstacle to fruitful communication.

Once the appointment starts, the different starting points is bringing a different range of risks for the communication gap. Patients will, for example, define a lupus flare very differently than doctors, focusing on differences in the way they feel, their experience of their disease, while doctors focus on biomedical tests and values. Even when patient and doctor align on the fact that there is a medical issue, like a lupus flare, their concerns develop in diverging directions. Immediate concern on quality of life (particularly over the next days) for the patient (How do I get organised? What does it mean for my work? Who will take care of the children?) combined with anxiety (Again a flare, will this ever stop?) contrast with the medication/comorbidities focus of the doctor (Should I change the treatment plan? What risks do I want to avoid?). With the mind focused on radically different considerations communication is difficult and requires deliberate effort to bridge the gap.

The concept of "treatment" is also different for patients and doctors. While doctors will typically mean prescribed medication, surgery, or physiotherapy. Patients define treatment as "Any product or activity that aims at improving the person with lupus' quality of life" [44]. This includes also non-prescription drugs, physiotherapy, sports, family, peer support, diet etc. This difference highlights the wish for a more holistic approach to health solutions and the aspiration to also discuss psychological aspects and exercise as part of the treatment plan.

Patients and doctors might have different expectations on the outcome of a given consultation. A patient might enter in the room with several specific (formalised or implicit) expectations from the visit: specific bothering symptoms, questions on medication, lupus impact, pregnancy, or relationship issues, new or potential symptoms, adherence issues etc and not find the space to raise them. When the consultation is finished, or when back home, the disappointment then appears.

Several topics remain quite sensitive and are difficult for the patient to bring up. The issue is exacerbated if they have the

impression that the doctor is also reluctant to openly address the topic. These difficult topics include fatigue (“my doctor never asks and does not care, saying he can’t do anything anyway”), sexuality (“who likes to talk sex with a person you meet every 3–6 months”), or adherence to treatment. On this last topic, possible reasons for the communication gap are many: don’t want to disappoint the doctor, guilt when recognising the “fault”, embarrassment, fear of not benefitting from the best treatment if acknowledging compliance gaps. Even when doctors open the discussion on one of these topics, communication often remains difficult.

Differences may also exist on the objective, the target of the treatment. This target is today more often discussed amongst doctors, in multidisciplinary teams in the best case, but in the absence of the patient. Are we looking at making lupus less active, at remission? With or without medication, at lower drug levels, or are we focusing on the suppression of specific symptoms? From a patient point of view, the choices might appear different: What dose of cortisone for what quality of life benefit? What daily life constraints to achieve a goal of remission without medication? Without any denial of the doctor’s expertise (“They are the one that studied medicine”), some (not all) patients want to be part of this decision and view treatment as a shared decision-making process. This process, which is likely to increase adherence to treatment, requires very good communication between patient and doctor, so that options, benefits, risks, and other impacts can be discussed between the doctor and their patient. To note, a treat to target discussion is not fit for all patients, some will by far prefer the doctor to set the target and the way, to avoid the anxiety triggered by taking a significant role in the process.

3.2. Skills and styles

As in any human relations, skills and styles impact the communication and the tone of the patient-doctor collaboration.

Cultural gaps are a first element: geographic origin, generation, economic situations all impact the general tone and distance that will prevail in the patient-doctor communication. Different therapeutic education levels must be considered to manage the communication, but also understand the patient’s expectations from the doctor.

Language impacts the patient-doctor communication at 3 levels: mother tongue, (health) literacy and tone. Beyond the obvious case of patients consulting in another language than their mother tongue, the health literacy will immediately impact the ability for the patient to describe their symptoms or the understanding they will have from the doctor’s perceived clear message (or not ...!). Difficult words, or the lack of nuances understanding (such as the usual question around organs being involved or damaged, permanently, or not) can create ongoing misunderstanding, but also “block” the patient’s ability to maintain a full participation in the balance of the consultation. A word is resonating and takes the full space in the patient’s mind while the doctor keeps speaking and nothing is heard. Finally, the tone used will open or close the patient’s ability to hear what is said and/or to share information. Often this will also reflect in the type of question used. Whether it be open-ended conveying a true interest, a concern and a space for the patient to speak. Or closed, leaving no place for a question of clarification or for a doubt. Importantly, the tone is also conveyed by the body language, which will make all the difference when a patient dares to ask a clarification and might either feel stupid or recognised for asking and encouraged to continue.

The patient’s own skills in managing the disease will also impact the patient-doctor communication. Patients with a higher level of education could potentially resolve a few issues independently thus leaving more time for tougher questions that might also be more rewarding for the doctor. In a small Lupus Europe poll, a majority of patients recognised that, when facing a question on their lupus, they will consult Dr Google rather than wait for the next consultation, and when they leave the consultation with questions on the doctor’s message, again Dr Google will be called to “help”. Yet, googling often brings low-quality answers; misleading, anxiety generating information or bad advice in forums. The recent initiative of www.lupus100.org [45] helps by bringing quality answers to common patient questions in their native language, validated by lupus expert doctors and patients. Access to this platform needs to become much broader so that it reaches the top of the list on searches.

Patients can help bridge the communication gap by preparing for their consultation, a skill that can be acquired. Examples include preparing a list of questions and concerns, identifying priorities, asking a trusted person to join in appointments for support, using an (online) health journal to objective symptoms over longer periods or learning with their doctors what symptoms matter for them. During consultation, tips include asking the doctor to explain medical terms and treatment options in plain language if unclear, asking for visual aids to improve understanding and clarifying to the doctor the role that they want to play in the treatment plan decision-making. Importantly, having an open communication, acknowledging objectively difficulties in therapeutic adherence, and providing straight answers will help save substantial time for other questions and avoid the doctor’s need to second guess!

Doctors should benefit from professional (continued) communication training as part of their education curriculum. This should focus on active listening and open-ended questions, identifying opportunities for language simplification and use of visual aids to improve health literacy, and building awareness of cultural differences. Other suggestions include creating feedback forms for visit evaluation. Most importantly, doctors can help bridge the gap by asking (with a convincing tone, not as a formality) to their patient if they have any additional point that they would like to raise, and clearly acknowledging that they have heard the patient’s worry or complain, even if they can’t do much about it. It is up to the doctor to decide how much of this complaint needs to be included in the assessment of the situation, but the acknowledgement will help build the communication.

Additional solutions to help bridge the communication gap will also come from the addition of a lupus nurse, which can provide substantial support, often in a more informal way before and after the consultation, helping the patient to sort through important or less important questions, confirming understanding of what was discussed in the consultation, or touching on some of the sensitive topics listed above in a softer context.

4. Are patient reported outcomes useful to overcome the communication gap?

There is a growing awareness that more patient-oriented research is warranted to address the multifaceted dimensions of the disease burden, with the final aim to improve the management of SLE. In this context, the potential role of PROs has gained growing interest.

However, their use in routine clinical practice is still very limited due to various reasons. Amongst these reasons is time constraints during outpatient visits.

Moreover, an ideal questionnaire has not yet been identified that can be feasible in clinical practice and be able to catch all the aspects of patients' life and their variations over time. To date, several questionnaires have been used for SLE patients, both generic and disease-specific questionnaires. Multidimensional disease-specific measures appear to have the strongest evidence for use in studies of adult patients with SLE. They include domains that are particularly relevant for the disease and may be more sensitive to capture fluctuations in health status. Further studies are required to evaluate these instruments for responsiveness [35,46].

However, maybe the most important aspect to define is the role of PROs in the care process, from both the physician and patient's point of view. PROs represent a tool to quantify qualitative information but they also facilitate rheumatologists in capturing the information about those aspects of patients' lives which might not strictly be related to the disease itself but could otherwise be overlooked. In clinical practice, it appears that PROs can facilitate doctor-patient communication and seem likely to improve satisfaction with the care received [47]. They can be useful to eliminate variability in the wording of questions and recording of responses as well as helping the patient remember relevant information, thus optimizing the use of time during the visits.

At present, from the physician's point of view, it remains difficult to translate the results of PROs into a treatment strategy, although it seems reasonable that they could represent important instruments to provide SLE patients with an opportunity to actively participate in their treatment.

Moreover, if prospective studies will bring more evidence of the correlation between PROs and long-term outcomes in SLE, PROs may become part of the data used to stratify patients at higher risk of complications and poor prognosis, thus guiding early therapeutic interventions, as recently suggested by Azizoddin et al. [40].

5. Conclusions

In conclusion, the communication gap between patients and clinicians is reflected by several unmet needs present in the management of SLE, from both the patient's and clinician's point of view (Fig. 1).

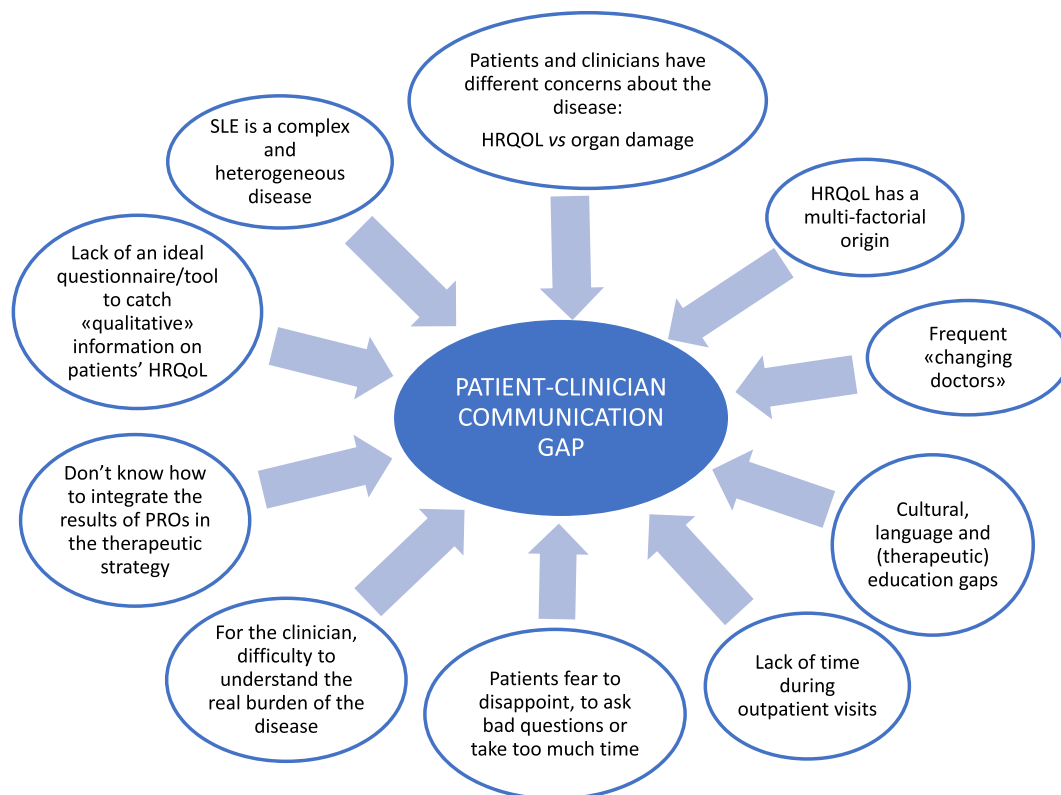


Fig. 1. Main determinants of patient-clinician communication gap in SLE.

Doctors and patients do have different visions and needs, and it appears imperative to find a way of integrating these two viewpoints [43]. To build a relationship which takes the form of an ongoing dialog and reaches a joint consent.

However, communication between patients and physicians is often inadequate in terms of both content and means and it is mandatory to find a strategy to improve it.

Bringing together clinical data and patient-driven data, will allow these two viewpoints to come together in a holistic, integrated picture. A positive patient-physician communication and a growing engagement of patients in the management of their disease are increasingly recognised as important instruments to improve patients' perception of health status.

6. Summary

Systemic Lupus Erythematosus (SLE) is not a single-target disease, and many aspects must be considered in its management. A "treat-to-target" strategy has been applied to SLE, however reaching the targets of remission and low disease activity is not strongly associated with an improvement of patients' Health-Related Quality of Life (HRQoL), which is influenced by many other factors. Therefore, it can be difficult for clinicians to identify the real burden of the disease on patients' lives: doctors are mainly focused on preventing organ damage, while patients' main concerns are all related to symptoms, like pain and fatigue, that impact on their HRQoL. Patients' and doctors' concerns develop in diverging directions, even when they align on the fact that there is a medical issue.

Patients too often feel they are considered as "the sum of biologic parameters" with no true consideration for the way they feel.

Time constraints during visits, "changing doctors" frequently, cultural gaps, different levels of patients' education do not help the communication between the parties.

Patient Reported Outcomes (PROs) seem to be able to facilitate the communication, eliminating variability in the wording of questions and recording of responses. However, most clinicians find it difficult to interpret and use the results of these questionnaires in the treatment strategy.

In conclusion, communication between patients and physicians is often inadequate in terms of both the content and means and this is reflected by several unmet needs in the management of SLE, both from the patient's and the clinician's point of view.

Practice points

Potential tips to improve patient-clinician communication GAP in SLE:

- Routine use of Patient Reported Outcomes that patients could fill in at home or in the waiting room before the visit so that the clinician can read and interpret the results during the visit with the patient.
- Provide the patients with some educational tools and informative materials (brochures, reliable websites etc) on the disease, treatment, drug side effects, lifestyle options to adopt.
- Optimize the use of time during visits preparing the consultation: e.g., it would be helpful for patients to prepare a list of questions and concerns, identify priorities, ask a trusted person to join in appointments for support; electronic diary to record clinical and lifestyle data collected during the daily routine may be of help.
- Improve doctors' communication skills through dedicated trainings as part of the physicians' education process.

Research agenda

- There is a need to identify the ideal core-set of PROs to use in clinical practice and for research purposes, to assess Health-Related Quality of Life and disease burden over time in patients with SLE, with the final aim to improve the management of the disease.
- There is a need to include patient-reported components in definitions of response to therapy, remission, or low disease activity in a treat-to-target approach.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

thank you to Daniela, Charite, Aldevina, Metty, Jeanette, Amy, and the Lupus Europe PAN for their contribution to the focus group on the patient side of the communication gap.

References

- [1] Guidelines for referral and management of systemic lupus erythematosus in adults. American college of rheumatology ad hoc committee on systemic lupus erythematosus guidelines. *Arthritis Rheum* 1999 Sep;42(9):1785–96.
- [2] Boddaert J, Huong DLT, Amoura Z, et al. Late-onset systemic lupus erythematosus: a personal series of 47 patients and pooled analysis of 714 cases in the literature. *Medicine (Baltim)* 2004 Nov;83(6):348–59.