

RESEARCH ARTICLE

Living with systemic lupus erythematosus: A patient engagement perspective

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Abstract

Patient engagement is recognized as a crucial component of high-quality healthcare services. Among rheumatic diseases, systemic lupus erythematosus (SLE) appears particularly challenging for the engagement of patients in their own care. According to the patient health engagement (PHE) model, patient engagement is a dynamic phenomenon that proceeds through four experiential positions (blackout, arousal, adhesion and eudaimonic project). The aim of the present study was to describe the engagement process from the point of view and the experiences of SLE patients. Ten in-depth interviews and four focus groups were conducted with an international sample of SLE patients from different European countries. Transcripts were analysed through thematic content analysis. Findings showed that a fully engaged patient results from reframing emotional, cognitive and behavioural dimensions. The advances along the process depends on how the patient succeeds in each position. In conclusion, PHE represents an appropriate model by which to understand the engagement process of SLE patients. In order to meet patients' needs, healthcare providers and patient support groups should consider the specific position of SLE patients, providing adequate and tailored support.

KEYWORDS

compliance, lupus, patient engagement, quality of life

1 | INTRODUCTION

Patient engagement is a crucial component of high-quality healthcare services, particularly as far as chronic diseases are concerned (Barello, Graffigna, & Vegni, 2012; Coulter, 2011; Gruman et al., 2010). It represents a key element for turning individuals into co-producers of their own health and enhancing their care experience, which results in improved health outcomes and lower healthcare costs (Graffigna, Barello, Libreri, & Bosio, 2014). More specifically, those patients who are more active and engaged in their care more frequently report better clinical outcomes, healthier lifestyles and more effective self-management skills (Alegria, Sribney, Perez, Laderman, & Keefe, 2009; Becker & Roblin, 2008; Hibbard & Greene, 2013; Hibbard, Mahoney, Stock, & Tusler, 2007; Skolasky, Mackenzie, Wegener, & Riley, 2008).

Systemic lupus erythematosus (SLE) is a rheumatic disease in which the engagement of patients in their own care is particularly challenging. Indeed, SLE is a serious autoimmune disease, most common in women, in which almost every organ may be affected and which exhibits considerable variation in disease manifestations between

individuals. The course of SLE generally involves periods of intense flares and periods of remission during which patients must be active and attentive in their daily care (Petri et al., 2012; Sutanto et al., 2013; Tan et al., 1982; Yu, Gershwin, & Chang, 2014). In the past few decades, treatments for SLE have improved and fewer patients are dying early in their disease. However, in order to reduce the possibilities and the intensity of flares, and to avoid consequent organ damage, patients generally need to make some behavioural changes in areas such as sun exposure, physical activity and adherence to treatment (Chambers, Rahman, & Isenberg, 2007; Millard, Hawk, & McGregor, 2000).

1.1 | Patient health engagement model

According to the patient health engagement (PHE) model, developed by Graffigna and colleagues (Graffigna, Barello, Riva & Bosio, 2014; Graffigna, Barello, Wiederhold, Bosio, & Riva, 2013), patient engagement is a dynamic and active process, featuring peculiar ways of interaction and decisional negotiation between the patient and the

healthcare system that depend strongly on the phase of the process. The PHE model includes four experiential positions: blackout, arousal, adhesion and eudaimonic project. The success of the patient in advancing along the process depends on how he/she succeeded in the previous phase. A fully engaged patient results from a series of emotional ("to feel"), cognitive ("to think") and behavioural ("to act") reframings of his/her health condition (Graffigna, Barello, Riva, & Bosio, 2014).

More specifically, the onset of the disease condition makes patients fall into an unexpected state of emotional, behavioural and cognitive *blackout*, which is perceived as being out of their control. In the position of *arousal*, patients are hyperattentive to signals from their bodies, and symptoms are perceived as a worrying alarm that may cause overwhelming emotional reactions. In the more advanced stages of the process (*adhesion*), patients acquire more knowledge and behavioural skills, so that they are able to comply effectively with medical prescriptions and feel sufficiently confident in their own emotional strength to cope with their illness. The last position of the engagement process (*eudaimonic project*) culminates in a patient having gained a positive approach to health management and recapturing an active role in society by re-establishing plans for wellness.

The PHE model has been developed from research studies in other diseases but its applicability and usefulness have not been investigated among patients with SLE. The aim of the present study was to apply the PHE model to describe the process of engagement of SLE patients, starting from their experiences.

2 | METHODS

An invitation to take part in the study was sent to people with SLE through the network of Lupus Europe members. Lupus Europe is the umbrella association of, currently, 24 national lupus self-help organizations from 22 member countries throughout Europe. The call was also published on the website and the blog of Lupus Europe. The participants were purposively selected in order to maximize the diversity of experiences, in terms of age, years from diagnosis, disease damage, involvement with patient organizations and country of residence.

Our work was guided by a phenomenological epistemology, which is about understanding people's everyday experience of reality (Holloway & Todres, 2003). Data were collected in two main phases. In a first phase, each participant took part in an individual semi-structured interview, investigating several aspects of life with the disease, from diagnosis to the present day. Interviews were conducted in a non-directive way, allowing the participants to report all of the life experiences that they considered to be relevant. Specific attention

was given to the manifestation of SLE and the perceived impact on patients' lives (see Figure 1). A preliminary version of the interview schedule was developed by one of the authors. Its content was then discussed and approved by the other authors. Minor revisions were requested by the ethical committee before the final approval. The interviews were conducted by one of the authors face-to-face or (when not possible) through a video call. Each interview lasted approximately 40 min.

In a second phase, the same patients took part in two focus groups (A and B). Focus group A focused on cognitive, emotional and behavioural strategies that they used to reduce the impact of SLE. Focus group B focused on treatment and the relationship with the healthcare providers (doctors, other professionals and organizations). The small participant group sizes enabled the focus groups to be intimate and highly informative. Each focus group was made up of four participants and one moderator, and it lasted about 1 h. One patient (participant 1) took part in the individual interview only. The groups were conducted in Brussels, according to researchers' guidelines, by two external SLE patients specifically trained for this task. All the interviews and focus groups were audio-recorded and transcribed verbatim. The combined use of face-to-face interviews and two focus groups for each participant allowed us to obtain the richest possible narratives. Indeed, face-to-face interviews allowed an individual exploration of the issues under study. The focus group represents a widely used qualitative technique that is particularly good for stimulating group discussion and exploring multiple perspectives.

A qualitative thematic content analysis was applied to the entire corpus of transcripts (Braun & Clarke, 2006). Consistent with our aims, the PHE model was adopted as a main coding frame and each reported experience was classified in one of the four positions (blackout, arousal, adhesion eudaimonic project). The first author proceeded with the analysis; two researchers read the transcripts independently and the final coding was agreed among them. The final results were also checked by the facilitators of the focus groups.

Oral and written consent was obtained from participants. All participants took part voluntarily. Approval for the study was obtained from the ethics committee of the first author's university (dated 15 February 2016).

3 | RESULTS

The mean age of the participants was 40.6 years (standard deviation [SD] 10.0). The average number of years since diagnosis was 15.5 (SD 8.6), with great variability in terms of disease manifestation (Table 1).

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| <p>0 – Presentation of the general aim and method of the study</p> <p>1 – The experience of receiving the diagnosis and the related reactions</p> <p>2 – Life with the disease (therapies and health behaviours, education/job, social relationships)</p> <p>3 – The relationship with doctors</p> <p>4 – Expectations for the future with the disease.</p> |
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FIGURE 1 Main themes of the individual interviews

TABLE 1 The characteristics of the participants

Interview number	Age (years)	Years since diagnosis	Main multi-system involvement (past and/or present):	Country of residence
1	56	20	Musculoskeletal, haematological, renal	Italy
2	27	3	Musculoskeletal, pulmonary	The Netherlands
3	37	15	Musculoskeletal	Estonia
4	42	24	Musculoskeletal, renal	Italy
5	48	17	Musculoskeletal, cutaneous, neurological	Finland
6	48	26	Musculoskeletal, cutaneous, cardiac	Spain
7	48	24	Musculoskeletal, cutaneous, renal, cardiac	France
8	41	<1	Musculoskeletal, cutaneous	Lithuania
9	24	12	Musculoskeletal, haematological, cardiac, renal	Belgium
10	35	13	Musculoskeletal, neurological, pulmonary, renal	Greece

Below, we describe how the PHE positions apply in SLE, focusing on the cognitive, emotional and behavioural strategies that are used by patients (Figure 2).

3.1 | The blackout position

In the period of pre-diagnosis, patients often live in a state of “suspension”. In SLE, this “blackout position” can even last for some years, and can also coincide with a period after diagnosis, in which the person has to face new and unknown symptoms:

They just told me that I had lupus, and I said, "What is it? Tell me what to do." [...] I had my myositis and infection of my kidneys. I was hospitalized for 40 days at that time. I was aching all over my body, my muscles. I couldn't comb my hair, I couldn't get rest, I couldn't walk. This was very difficult. (Participant 10)

In the last year, I started being worried about lupus. Before, I was okay. Even if I knew that I had lupus, I was enjoying life. Now, I'm very worried and I cry quite often. In the evening, I think about my recent heart attack and I'm afraid. (Participant 7)

In this position, patients (similarly to members of their close social networks) do not have a clear representation of the illness:

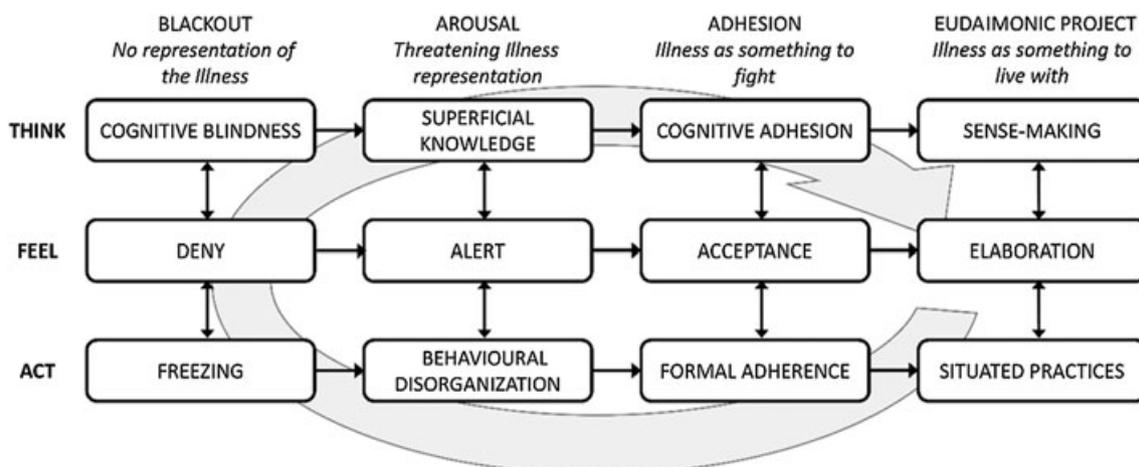
But in those years, lupus was very strange. I remember when I talked with friends, "Yes, the doctor says that I have lupus". "Lupus? What is that?" (Participant 6)

Individuals are largely unequipped in term of coping strategies. They feel blocked and do not know how to deal with the new condition. In the meantime, they go through a series of clinical evaluations, by the general practitioner and specialists:

One evening, I had terrible pain in my knees, and I had a fever. I couldn't move very well anymore. Then I went to visit my family doctor. She saw that my blood analysis was very, very bad and she said that she didn't know what was going on. Then she had to send me to a specialist. Then I waited some 3 weeks [for] this appointment. During that time, my situation became even worse. It was really, really hard to move because of the pain. ... It was really like, "Well, what's going on? Why am I not able to do those things anymore?" (Participant 3)

At a cognitive level, this position is characterized by a “cognitive blindness”, which implies a focus on the present situation and an inability to plan for the future. For some participants, this blackout may also result in difficulties in recall:

I remember very little from that period - it is like a black hole for me. Almost as though I wasn't present for some of

**FIGURE 2** The health engagement model for systemic lupus erythematosus patients (adapted from the model by Graffigna et al., 2013)

the time. I was so busy with myself... I didn't have plans for the future, but I had "this day", "this moment".
(Participant 3)

Patients often do not have any specific knowledge about SLE, so the first information that they receive about this condition and its consequences is extremely important:

It is very important that the doctor who is diagnosing you speaks to you in the right way, the correct way, to explain things to you but without overloading you with all the problems all at once because you have to face a problem and people don't usually know anything about that. You need time to learn.
(Participant 1)

In this context, the acceptance process is just the beginning, and patients try to deny the disease as much as possible, and not allow the negative emotions (such as fear and depression) to overwhelm them:

Let's say that at the beginning, I was scared. Yes, I cried, and I was... I felt worried because of all this and I wondered, why [has] this happened to me, and those kinds of things. (Participant 3)

When I felt bad, it was even harder for me. We say "vicious circle". You have to stop the vicious circle before it begins to create a hole. Yes, it could be too late. I think I could develop depression. (Participant 5)

This state of confusion may also be reflected in the persons (relatives, partners, etc.) who are close to patients:

One day, suddenly, red spots appeared on my face, here. I didn't know what it was. Slowly, on my face appeared the shape of a butterfly - the butterfly rash. ... Doctors didn't know... It was awful for me, for my parents, for my brothers, all my family. It was a very hard experience because I was younger and I felt that... I wondered if perhaps my face would be like that forever. It was very hard. (Participant 6)

3.2 | Arousal position

In the second position of the engagement process, patients start to consider SLE as something to cope with, but are not able to identify efficacious strategies. SLE is perceived as very threatening, still unfamiliar and largely unpredictable:

You mentioned something that you thought of lupus sometimes as kind of being lurking in the background.
(Interviewer)

Yes. ... It's quite creepy sometimes. I sometimes felt that it's like an alien inside me. (Participant 5)

In this position, knowledge about the disease is still superficial. Moreover, the complexity of the mechanisms of action of the

treatments prevents a cognitive understanding of the rationale behind the medical prescriptions. Even if patients can benefit from the first medications, their adherence to the treatment still appears to be fairly unstable:

I was sick with thyroiditis. My thyroid is very, very small, and I had to take additional L-tyrosine ... I didn't question this treatment because I really understand it. It's logical to me. You don't have the thyroid, you have to take the hormones. This is clear. But when I know that the disease [SLE] is really unknown, [a] very individual path, then I'm naturally asking, "Is this the right thing for me?" (Participant 8).

At an emotional level, patients in this position may experience feelings of isolation and look for role models and examples from other patients, in order to figure out what is happening to their body and how the disease could affect their lives. In this search, they may also receive suggestions about the management of the disease from non-scientific sources:

I know that some people want to believe in everything. Some people try to get help also from the so-called "witches", and in my country it is pretty popular to ask or to get your help from nature.
(Participant 3)

In order to overcome the perceived loss of control over their lives, patients start searching for as much information as possible about the diagnosis, sometimes guided by unrealistic hopes:

I started, I tried to start to find information about the disease. Then, probably, I had this feeling that maybe doctors were wrong. For many years, I thought, "Maybe I still don't have this lupus. Maybe they made the wrong diagnosis". (Participant 3)

In a similar way, patients in this position may also overestimate the positive impact of their behaviours, and can start adopting self-made diets or treatments:

Instead of taking hormones, I'm doing physical exercise every day, one and a half hours at least. Maybe it will sound crazy, but I really hope that my body will become healthy if I exercise, if I nourish myself well.
(Participant 8)

3.3 | The adhesion position

In this position, patients understand the physician's prescriptions but they cannot completely accept the illness as part of their life. SLE is described as something that is threatening, but also controllable through the prescribed treatments:

Once, the neurologist told me, "It is as though you are on some stairs and you don't know the moment when lupus will push you down them..." So, avoiding steroids would be a real risk. (Participant 4)

They are able to identify efficacious strategies to help them in organizing their daily activities and in remembering to take the prescribed medications:

I have a little box every day. I can show [you] it. Just like this. Can you see it? Every day, I take one. And I have alarms on my mobile phone, alarms every day. I won't forget it, I never forget it. (Participant 2)

Moreover, in this position, patients are able to see the positive impact that the continuous use of adequate medicines can have on their quality of life:

Life is difficult everyday – day after day. But with medication it has been wonderful because I have worked, and I have always been able to work. (Participant 6)

According to this, patients are willing to follow the specialists' prescriptions, even if they have difficulties in taking control of the management of the disease. Prescriptions are often seen as external norms and their function is not entirely clear. It can be particularly difficult to obtain a coherent picture from the different (and sometimes inconsistent) views of specialists:

So, I had to see many specialists, but I have the impression that they do not communicate, and that there isn't one doctor who has an overview of everything [...]. Everybody looks at each thing, but there is no contact between the different specialties, so that's very difficult as a patient. You are always bounced from one doctor to another, and sometimes it's tiring. (Participant 9)

Sometimes, this position also coincides with new opportunities to meet other patients with a similar diagnosis. This can be perceived as a useful occasion to overcome social isolation and to enhance the feelings of being understood:

When I met those girls, I understood that I'm not alone. They have many similar problems, even though some of them are different. But I felt that I am not alone anymore and I can share [my thoughts] because I know that some people may have a deeper understanding of what's going on with me. (Participant 3)

3.4 | The eudaimonic project position

The patients in this position are able to set up an adequate system of cognitive, emotional and behavioural responses to the disease. The representation of SLE is less threatening, and can be described as an inseparable companion, and even a part of the self:

I was talking with my husband recently, and I was telling him that I can't remember my life before lupus. I have reached a point where I love my disease. (Participant 10)

Patients in this position are informed about the disease and related treatments. They pay great attention to the doctors' advice and are willing to consider new treatments in the presence of

supporting scientific evidence. This position is characterized by the possibility of making plans for the future, and patients are able to redirect their energies into activities that they can still perform, even with the disease:

I want to have my plans. I want to work. These are very important to me. I want to travel, and through my experience I want to help people with lupus ... It is life. We must accept whatever comes and try to improve it. (Participant 10)

Like the adhesion position, the eudaimonic project position is characterized by adherence to prescriptions. However, in the last position of engagement, individuals discover and actualize their personal responsibility for their SLE self-management, and they are able to discuss their treatment options with doctors:

I always speak to my doctor before I change something. I never do it on my own. Yes, I talk to her, I think, and ask her, "What do you think about it?" Then, we discuss [it] together and then we decide what to do ... I've got my own opinion and she listens to that. (Participant 2)

Participants expressed their unmet needs and expectations relating to access, through the healthcare system, to the newest drugs, including biologics:

I think a drug could be very useful, and also to be given it at the time you need it, not to have to take it after a series of other drugs ... You need to have taken other drugs before you get the newest drugs that have been discovered. (Participant 4)

Patients are conscious that they need different specialists but are able to maintain a fruitful collaboration with each of them. The patients themselves are the "leaders", but understand the importance of coordination and collaboration between doctors:

The doctors organized this very well. When I had an appointment with my rheumatologist, they made an appointment with the haematologist at the same time, on the same day, and they were together in the same room with me, and discussed everything together ... It should always be like this. (Participant 3)

Now, I know the doctors who specialize or are specialists in the different areas. So, at first I saw a rheumatologist, then a neurologist, and then also a haematologist. And I've known them for a long time now We have very good communication – it's a very easy relationship. (Participant 1)

In this position, patients are more conscious of their psychological and emotional needs, which can go beyond adherence to medical treatments. In a similar way, they emphasize the importance of the process of psychological acceptance of the disease:

Medication adherence: this is very important. But the emotions and psychology are also very important. (Participant 6)

I would like to keep a positive attitude. The acceptance of the disease is the primary consideration. (Participant 10)

Similarly, some of the patients in this position recognize the specific importance of the psychologist's role:

I think that psychologists have the right questions... they can help you to understand a lot of things that many times, you can't see. Because your life is people, house, family. If you have children, children. The problems of every day. This is very important for me, yes. They work on emotions, and psychology is very important. (Participant 6)

4 | DISCUSSION

In this study, we examined the experiences of a group of SLE patients, adopting a patient engagement perspective. Our findings suggest that the PHE model (Graffigna, Brello, Libreri, 2014; Graffigna, Barello, Riva, et al., 2014; Graffigna et al., 2013) represents a useful framework to improve our understanding of patients' experiences with such a complex disease.

Some specific properties of SLE should be considered. First, the advancements in the engagement process seem to be inevitably accompanied by changes in the representation of the disease that gradually become more definite and less threatening (Mazzoni, Cicognani, & Marchetti, 2014).

Second, PHE in SLE is not a linear process and it is characterized by obstacles and setbacks. The positions of the PHE are ways of approaching the disease that can appear more than once in the patient's story – for example, when new symptoms appear.

Third, the passage from one position to the following one does not inevitably concern every patient. Even if the empowerment/collaborative approach that characterizes the eudaimonic project represents the final goal (Anderson & Funnell, 2000), none of the positions of the PHE model is “superior” to the others. Each position may be functional when patients are facing specific disease challenges, and may last for a longer or shorter time.

The present study has strong practical implications. Nowadays, the challenge is both to guarantee the achievement of good clinical outcomes and to increase the sustainability of healthcare organizations. The patient/consumer of health services should be considered as an active partner and a potential resource (Graffigna, Barello, Riva, et al., 2014).

The PHE model suggests action priorities that, fostering the patient–health provider relationship, may function as a catalyst for the care process (Graffigna, Barello, Riva, et al., 2014). The support given to patients should be tailored to the specific needs and representations of the disease that characterize each position. For example, one of the action priorities to promote the transition from the *blackout* to *arousal* position is to foster an initial understanding of the disease (see also Waldron et al., 2011). This means supporting patients in the management of unexpected emotional disruption, establishing a trusting relationship between patients and doctor, providing focused information according to the patients' attitude to receiving and

elaborating on this. The action priority for the transition from the *arousal* to *adhesion* position is to make patients more confident and effective in the management of the disease. This includes supporting patients in understanding the functioning of the disease and the usefulness of care prescriptions, in order to reinforce their compliance with treatments. Finally, to reach the *eudaimonic project* position, it is important to sustain patients in making new life plans and maintaining a healthy lifestyle, and this implies good coordination between specialists (see also Mattsson, Möller, Stamm, Gard, & Boström, 2012).

Some limitations of the present study can be identified. The PHE model represents a simplification of reality. Several studies have identified different patterns of disease in SLE (Pons-Estel, Alarcón, Scofield, Reinlib, & Cooper, 2010). Patterns of clinical history and manifestations of the disease may have different consequences for the engagement process. Moreover, the study did not benefit from an external peer review of the data analysis, and participants were not directly involved in the data analysis process.

Finally, the qualitative nature of the study and the characteristics of the sample under study did not allow our results to be generalized to the entire population of SLE patients. However, recent attempts have been made to measure patient engagement quantitatively (Graffigna, Barello, Bonanomi, & Lozza, 2015). Future studies will partially overcome such limits, also allowing a quantitative assessment of variables and their reciprocal relationships.

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