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## Life course changes provoked by chronic disease: A study on everyday life for patients with systemic lupus erythematosus

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### ABSTRACT

**Objective:** This study examined patients with systemic lupus erythematosus (SLE) as a means to explore the impacts of chronic disease on life courses.

**Methods:** A semi-structured in-depth interviews were conducted with nine patients in China in 2017; participants were included based on their having or having had facial butterfly erythema.

**Results:** The study focused on both the disease's impact on the patients' health and on their daily lives. Four core themes emerged: visible changes in the patient's bodies, social dilemmas, "the encouragement of disease", and a new perspective on the relationship between disease and health. One important finding was that the occurrence of a chronic disease did not have only negative repercussions; some patients felt that there were advantages to being sick. Chronic disease resulted in a reworking of daily life. The patients developed a self-referential model of healing.

**Conclusion:** The distinct interpretations of the same disease offered by different patients served to yield a more complete understanding of the disease. People with SLE adjust their thinking about the disease based on personal feelings as well as experiences and pursue a dialogue on their illness based on the disease pattern unique to them. The meaning that disease had for the patients was not limited to negative connotations.

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### What is known?

- Systemic lupus erythematosus (SLE) is a complex and typically chronic illness that may cause inflammation activity and damage in any of the organs, often resulting in decreased physical, emotional and social abilities, depression, pain, fatigue, visible or invisible changes in appearance. Patients with SLE may develop body image concerns from multifold reasons, of which only some may be due to externally visible characteristics.
- Following a flare of SLE there is often a lingering sense of threat, and the feeling of a setback-in-life persisted long after the disease was medically under control. Patients with SLE are likely to be stigmatized and often treated indifferently.

### What is new?

- The way SLE patients think about the disease is based on their personal feelings and experiences, and they pursue a dialogue on their illness according to respective disease patterns. The meaning that disease had for patients is not limited to negative connotations. SLE patients would confront both the problem of treating the disease as well as the challenge of how to maintain and develop their social relations. This problem could not be solved by medical treatment. Rather, it calls for the efforts of both patients and society.
- With the control of the disease, SLE patients could re-examine the relationship between "disease", "body" and "self", and finally accept the existence of the disease. Chronic diseases could have diverse sets of meanings in illness narratives, during an experience of illness, negative emotions—such as grief—comprise only one part of the entire process.

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### 1. Introduction

Systemic lupus erythematosus (SLE) is a chronic, autoimmune inflammatory disease, with a broad and varied clinical picture [1].

Although the survival rate of SLE patients has improved significantly, it currently remains impossible to completely cure, and life expectancy is shortened because of the disease. The overall pooled survival rates from 1995 to 2013 for SLE in China were 94% for the 5-year survival rate and 89% for the 10-year survival rate after the onset of disease [2].

Common clinical manifestations of the disease include skin rashes, uneven pigmentation, vitiligo, scars, loss of teeth, alopecia, facial hair, stretch marks, weight gain, fatigue, pain, depression, unpredictable flares, and a loss of independence [3]. About two thirds of patients with SLE will present facial erythema, pigmentation, light sensitivity hair loss, skin ulcers and muscle fiber pain [4]. Physical symptoms, such as sensitivity to sun, joint pain, malaise and fatigue, can be daily reminders of the illness [5]. The visible manifestations of the disease may directly affect patients' daily life. Both social isolation and poor body image have been documented among patients with SLE [6]; young women, in particular often struggle with body image issues [3]. Concerns about body image have led to patients' increased social isolation and decreased communication.

Most patients experience negative emotional reactions to varying degrees over a considerable period of time. Their psychological and social functions also are affected. Individuals affected by chronic or life-threatening illnesses do not always experience them in terms of danger or loss. However, following a flare of SLE there is often a lingering sense of threat, and the feeling of a setback-in-life persisted long after the disease was medically under control [5]. A previous study found that five SLE patients made seven attempts at suicide over 20 years; one of them was fatal. Chronic physical illness has represented an important risk factor for suicide [7].

Most studies of SLE patients have focused on health-related factors but overlook the phenomenological study of patients' illness and daily life. The emergence of SLE makes the duration of illness indefinitely delayed, which means that the duration of illness may be lifelong. Chronic illness represents a more radical change in the basic conditions of life and therefore has the potential to result in patients' structures of meaning. Moreover, chronic illness can be a great source of suffering [8]. Acceptance of one's illness usually demands time. Chronic illness is conceptualized as a particular type of disruptive event. The disruption is characterized by a reworking of the ways that a patient may understand pain and suffering. Patients tend to seek information on SLE and observe their bodies. Over time they may learn to recognize the symptoms of aggravation and become able to better organize their work schedules and other responsibilities to accommodate the time when they are indisposed. Patients frequently develop strategies to cope with the disease [1].

The research presented here was designed to identify the salient parts of SLE patients' daily lives and the shifts that occurred in their life course as a result of the disease. The objectives of the study were three-fold: 1) to identify the impact of chronic disease on patients' daily lives; 2) to analyze the practices of self-care in which the patients engaged; and, 3) to re-examine the findings from previous research on the impact of chronic disease on life courses [9].

## 2. Methods

### 2.1. Study design

Understanding how a person lives with chronic illness is necessary to help the patients adapt to the disease. Qualitative research provides rich information about the meaning that people make out of their experiences, as well as the emotions and processes they experience [10,11]. One of the advantages to qualitative

research is the ability to develop a positive rapport with participants, thereby enabling greater insight into the subjective experiences of illness. Kleinman analyzed what he referred to as patient "illness narratives" [12]. This study explored the impact of SLE on the individual through the lens of illness narratives. Analysis of the narrative discourse included six dimensions: characters, setting, events, audience, causal relations, and themes [13]. Data was collected from semi-structured interviews. The significant advantage of semi-structured interview is the opportunity for previously unknown information to emerge.

### 2.2. Participants and sampling

The research subjects in this study were selected using the *classification criteria of SLE* provided by the American College of Rheumatology [14]. Due to the numerous classification criteria of SLE, as well as the absence of medical data collected during this study, participants were included based on their having or having had facial butterfly erythema. All of the participants were 18 years of age or older and able to participate independently. Minors and individuals with guardians were excluded from the study. Patients were selected from two sources. The first source was a grade-a tertiary hospital in Nanjing, China, where the rheumatology and immunology departments provide specialized SLE outpatient services. The hospital's fixed-point research represented an important way to contact patients. In this study, the patients were introduced by the attending doctors and the other patients introduced by the patients were recruited continuously through "snowball sampling". The second source was through online networks. The researchers posted on relevant websites, such as Baidu Post, the researcher asked potential participants to respond four questions: 1) Have you or will you ever gone out publicly with erythema? 2) Are you 18 years of age or older? 3. Have you had the illness for at least one year? And, 4) would you agree to the video taping of interviews? Following interviews of all eligible patients with no new information regard to more participants, the recruitment process was ended, then the information will be viewed as saturated. A total of seven patients (A1-7) were recruited from a hospital specialty outpatient lupus clinic and two patients(A8-9) were recruited from on-line sources. Recruitment took place from June to October 2017.

### 2.3. Ethical consideration

The study was followed the World Medical Association Declaration of Helsinki [15], signed written informed consent with all interviewees before the interviews to ensure the privacy of interviewees and other issues, including not using the patients' names and refraining from taking photos or videos without the consent of the patient and other content. The study was designed to respect the principle of patients' voluntary participation in the interview, protect the privacy of the interviewees, avoid questions or responses that the interviewees would be unwilling to share or publish, and designate a time and place according to the needs of the interviewees. The autonomy principle underpins the ethical demand to obtain a person's properly informed consent to participate in a particular study, and to allow them to withdraw from studies at any time [16].

### 2.4. Data collection

Nine patients were interviewed. Their ages ranged from 19 to 57 years old. The interviews were conducted from June to November 2017. All interviews were conducted independently by the researcher. The interviews were conducted in hospitals and cafes near the patients' homes and lasted between 40 min and 2.5 h.

Previous studies on SLE were used to identify difficulties experienced by patients to include in the interviews: “visible physical changes”, “change of mindset”, “ways to hide erythema”, “social anxiety”, “privacy protection”, “acceptance of SLE”, and “impact of disease”. All of the participants were asked for a description of the time when they learned that they had the disease and whether they believed that the changes in their appearance would affect their social relationships. In order to explore the changes caused by the disease in the participants’ daily lives, they were asked to elaborate fully in their responses to questions such as “What do you think it means to you?” Each of the interviews was recorded and transcribed. Additionally, the researchers recorded any observed body movements, gestures, and expressions.

The patients’ feedback served to identify topics that should be included in the interviews. The interview questions were adjusted for the study based on the experiences obtained during the interviews with A1 and A2. For example, only phone numbers were collected for patients who were unwilling to add a researcher’s WeChat. The study added “Why not add my WeChat?” to the questions asked. Additionally, return visits were made to A1 and A2. Also, all respondents said that they would strengthen their sun protection after the occurrence of “erythema”. Therefore, “hide of erythema” was added to the topics covered in order to understand how patients hide erythema and why they are eager to hide erythema. Finally, this study conducted two initial interviews with each patient and a third supplementary interview to further examine some of the details provided by the patients later in the study. Table 1 shows the demographic information of the selected participants.

### 2.5. Data analysis

During the interviews, the researchers took detailed notes. The interview notes focused primarily on salient points that emerged and identified interviewees’ emotional changes. Following each interview, preliminary excerpts from key responses also were recorded. The transcripts of the interviews were used to identify keywords in each of the interviews. The researchers employed the methods of discourse analysis and separated the data collected into seven topics; four of the topics are described in depth.

## 3. Results

The following four themes describe the daily life of SLE patients: 1) visible changes in the physical body; 2) social dilemmas; 3) “the encouragement of disease”; 4) a new perspective on the relationship between disease and health (see Table 2).

### 3.1. Visible changes in physical body

Through interviews and participant observation, researcher

found that physical changes represented an important turning point in their daily lives. The patients experienced changes over the course of disease development—from the time of the appearance of symptoms, during their diagnosis and treatment, and upon their return to normal life. Health/disease is determined by interactions between the mind, body, and the surrounding environment, and the skin is the interface between the body and the external world [17]. Classic erythema on the face, discoid lupus rash, lesions with a tendency to scar, skin atrophy, and loss of hair often proved unsightly and lowered a patient’s self-esteem. These symptoms made them feel embarrassed by their appearance [1]. Following the onset of erythema, the patient had visible body changes; these changes impacted their bodies and identities. The identity of patients changed from healthy individuals to patients. As a result, all the patients shifted their focus to a greater surveillance of their bodies. Living with systemic lupus erythematosus was compared to as a “vampire” (A3); patients needed to avoid light and felt tired. Patients clearly distinguished different stages of the changes they experienced that corresponded to the times of onset, treatment, and return to daily life. The identification of, attempts to hide or cover, and overcome erythema, represented three moments that were accompanied by psychological and behavioral changes. In their descriptions of the illness, most of the patients did not refer directly to the disease, but rather to particular details of their lives at the time. For example, A1 stated that, “the year of the diagnosis was in the winter when my son just came back from winter vacation. He accompanied me to do the medical examination.”

The moment that they began to experience symptoms was when the participants communicated with doctors or the outside world. It appeared that the act of describing the illness represented the moment when that link between illness and everyday life was established; feelings about the body and cognition were reorganized. The participants seemed to hold onto the time of onset as a defining moment that separated health from illness; that moment was accompanied by a major shift in their perceptions of their lives.

Erythema is the most obvious physical reaction and characteristic that served to determine a patient’s condition. Different patients manifested distinct physical symptoms and reactions. A9 noted:

*At first, there were small pimples on my face. I didn’t take it seriously ... Almost half a year later, it slowly turned into erythema, which continued to form lumps and became particularly frightening.*

Patients had different degrees of erythema, they typically would take hormones during the treatment process. The use of hormones would lead to swelling, hair loss and other obvious physical changes. Patients would compare the body image from before and after onset of the disease. For example, A7 noted, “I was 100 pounds before the disease, and reached 130 after the disease.” A7 showed

**Table 1**  
Demographic Information of SLE Participants in this Study (n = 9).

Participants Number	Age (Years)	Gender	Marital Status	Employment Status	SLE Duration (Years)
A1	55	Female	Married	Retired	7
A2	28	Female	Single	Employed	8
A3	25	Female	Single	Student	5
A4	57	Female	Married	Retired	5
A5	28	Female	Single	Employed	5
A6	19	Female	Single	Not employed	3
A7	27	Female	Single	Employed (part-time)	6
A8	32	Female	Divorce	Employed	4
A9	31	Female	Married	Not employed	3

**Table 2**  
Themes and supporting quotations.

Themes	Subthemes	Supporting Quotation
Visible changes in physical body	a) The appearance of “erythema” b) Strategies used to hide disease: cosmetics and clothing	a) Almost half a year later, it slowly turned into erythema. (A9) b) Covering the erythema with foundation makeup makes me feel better. Also, make-up gives me a sense of security, and I become more confident. (A3)
Social dilemma	a) Social anxiety and privacy concern b) “Net friend” on social media	a) I will not tell you if I am presently in the hospital now. I would say that the worst I have is an allergy. (A8) b) I feel very relaxed when chatting with them, and I dare to say anything. (A5)
“The encouragement of disease”	a) Explore the “advantages” of the disease and make adjustments in work and personal life b) Pay more attention to individual health	a) I told my boss that I was ill and want to change my post. To my surprise, he finally agreed. (A8) b) Regular examinations could prevent other diseases. (A5)
A new perspective on the relationship between disease and health	Self-suicide and self-atonement	At last, I think up a truth, which is that illness is not the entirety of life. (A8)

photos from before the disease to the researcher, urging researcher to identify and accept with their past image.

The participants with impaired body images felt that they had become “weird” (A4) in the eyes of the outside world. Therefore, they felt compelled to find ways to hide the outward appearance of the disease. Participants created an alternative identity for themselves through the use of make-up and concealing clothing to hide their illness from others. They wished to “look like normal people” (A3). Especially the young women would devote attention to the management of the image they projected; make-up became a necessary means to control their outward appearance and achieve a “healthy” image. For example, one young participant (A2) stated that, “I can only rely on external accessories such as scarves, masks and so on for partial cover”.

A2 also hoped to hide her erythema through cosmetics. However, it was not wise to attempt to hide erythema through the use of cosmetics. Not only do they not restore health, but they also can draw increased (and often unwanted) attention to the person. As A4 noted, “Nanjing’s summer is so hot, I can’t wear short sleeves. Once outside, hats, glasses and so on need to be worn.”

Covering up would help to avoid direct sunlight but did not necessarily achieve the attempt to go unnoticed. Excessive clothing used to conceal resulted in the participants feeling strange in a crowd. Patients faced more—not less—public attention. The shift from a focus on the body to one on “body decoration”, provoked a change in the participants’ external image. Therefore, the changes experienced were not limited to the body alone, but also to the external “decoration” of the body. As A3 mentioned, make-up could make one feel more confident, and that would improve social interaction. The ability to maintain the appearance of a healthy body to display to others proved important. This practice was not related to an attempt to improve one’s condition, but to obtain social acceptance and tolerance.

### 3.2. Social dilemmas

Individuals encountered difficulties in their attempts to maintain their normal social interactions after they began to suffer from the disease; these social challenges represented an additional injury that they sustained. They would pursue connections through Wechat and/or QQ to continue on with daily life. However, the importance of these connections indicated a significant change in the ways that they interacted with others following the diagnosis of the illness. The participants were forced to change the ways that they interacted following the illness by placing greater emphasis on extending their social life to new spheres, such as the Internet. In that way they were able to develop connections with others who

also were battling the disease.

Patients often wanted to find an “online patient” platform according to their social media use. For young patients, social media use helped them to reconstruct social relationships. They also were interested in choosing websites. A2 and A3 chose Douban(Community website, which provides a variety of service functions) and Zhihu(Online question and answer community and a platform for users to share their knowledge and opinions). They thought that they could obtain better professional responses with regard to their illness on those sites. Other patients, such as A5 and A9, chose Baidu Post because they thought that they would be able to find a greater amount of sharing about the disease. Regardless of whether it was Baidu Post, Douban or Zhihu, the choice of social media reflected the social media use habits of the patients. Individuals chose to explore the platform about illness and made friends as they would have socialized in the past. They sought others who were like themselves. The search for information about their illness represented important Internet activities. Consequently, the Internet was a vital medium for patients to rapidly acquire a “net friend” and extend their social sphere. For example, A5 stated,

*“I feel very relaxed when chatting with them, and I dare to say anything. Most importantly, we understand each other, and know the sufferings of this disease, which cannot be understood by others. This is just like that I met the previously known friends at present occasionally.”*

Some patients noted that initially they searched the Internet for the characteristics of SLE to better understand symptoms and treatments. However, they came to discover that SLE is not well-known or accepted. A4 noted that, “even though we all have SLE, we would not like to tell others about our disease. I would not like to share it, even though I am asked.” In real life, the participants were unwilling to communicate with others with the same disease. A4 expressed her concerns:

*“I don’t know whether they share the same illness with me and whether I should tell them that I have SLE if they have other diseases. On the other hand, what if I did? It is a burden to tell, no matter whether they have more severe or moderate illness than me.”*

The patients struggle with how to communicate with the outside world. The friends made on the Internet offered an important source of support and spiritual uplifting. A3 mentioned that she shared with a net friend what she could not share with

family:

*“I know this disease has deprived me of the chance to get married and give birth to babies just like the normal girls, including a sex life. I don't know what to do now and am quite confused.”*

The participants noted that they were extremely alert when interacting with strangers. They proceeded with great caution so as to protect their privacy. A5 noted that she would not like strangers to check her “Wechat Moments”. The participants yearned to return to their normal social environments, but the developed practice of self-protection and heightened sense of social boundaries had created additional obstacles to their being able to do so. Most of the participants refused to add the researchers on WeChat after their first meeting. They believed that the researchers would contact them for the research and interviews and consequently did not meet the criteria for a person with whom they would pursue a deeper relationship.

Upon learning of their illness, the participants initially would prove reluctant to share about their illness with others. They hoped to have more opportunities for social interactions and manage others' impressions before they share about their illness. As A10 noted, *“sometimes it is boring because no one understands me, but I would prefer not to say anything when I am asked.”*

Sensitivity, excessive concern for privacy, and an attitude that prioritizes self-protection clearly fortified the boundaries around the participants' social interactions. At the same time, the patient attached great importance to feedback received from the outside world. For example, when meeting with the doctor, they would carefully observe the doctor's attitude and expression, and even speculate about the doctor's description of the disease. A8 noted that, *“as soon as the doctor would come to check the room, immediately I would ask him. Sometimes he would say something and I would mull it over for a long time for fear of problems.”* The behavior, language and even eye-to-eye contact could prove important to achieve a shift in their perception of the external environment and changes to their behaviors.

After repeated contact with the patients, the researcher was able to break down some of those barriers. Individuals agreed to add the researcher's Wechat and were willing to actively talk about the disease with researcher. This seemed to represent a good sign that the patient's lines of defense around social boundaries had been broken. It seemed that the patients' privacy and boundary issues had created a barrier to social interactions. Once the participants pulled themselves away from their original social networks, they proceeded by tightly managing their social relations; they strove to build new social networks suitable to their current situation.

### 3.3. “The encouragement of disease”

For SLE patients, the influence of disease changed and even weakened as time passed. The participants regarded the symptoms of the disease as a part of their bodies. Attitudes about the disease shifted from completely negative to neutral, and even to optimistic.

One of the most interesting findings from this study was that the experience of disease represented an important turning point in their lives, bringing with it *“the encouragement of disease (A9)”*. For example, A2 asked for an accommodation at her job, noting that she was *“not able to overwork due to illness”*. The disease was an opportunity for the participants to make major decisions that they might not have otherwise. Even when they did not necessarily expect positive responses, illness encouraged them to actively address external events in their lives. It also permitted them to take

advantage of certain privileges. Not all of the impacts of having become a patient were negative. After becoming sick, individuals were no longer limited by their original social identities. They depended on their role as patients to pursue strategies to care for themselves. For example, A2 pursued a job position that better suited the needs she had as a result of the disease; this was a novel experience for her.

The participants adapted to changes in their identities, as well as to the impacts of the disease. They gradually transitioned from being people who enjoyed good health to ones that depended on regular doctors' visits and continued to struggle with erythema once the condition had stabilized. The patients adjusted their understandings of their bodies. Consequently, they reworked their perspectives on the disease, accepted their new identities, and embraced a willingness to move on with their lives. Chronic disease not only challenged their physical health, but also impacted the participants' attitudes towards life. After having lived for several years with SLE and the conditions had been stabilized, most patients were able to face their illness in a frank and optimistic way.

The participants were able to adjust emotionally to the disease and face its impacts with a positive attitude; they even were able to identify certain advantages to having a disease. For example, A5 noted that the illness possibly allowed her to stay healthy in other ways. As she noted, *“it is not bad. The regular examination also helps prevent other diseases.”* Although the damage to the patient's physical condition persisted, the individuals were able to adjust their mental state and resume their daily lives. The disease also became a justification for ceasing activities that were no longer enjoyable. The participants began to focus on aspects that truly mattered in their lives [18]. Thus, their chronic diseases ceased to be an impediment in their lives.

### 3.4. A new perspective on the relationship between disease and health

In this study, all nine patients clearly expressed the belief like *“if I were not sick, my life would be totally different from what it is now”*(A3). Three of the participants (A2, A3, A8) clearly indicated that they had experienced suicidal ideation and even acted upon it. Their experiences with the disease were overwhelming to the point that they felt that they could not bear it. However, after the initial period of illness, all three patients considered suicidal ideation as *“an unwise choice”* (A2). Survival with illness became the patient's choice. As A8 mentioned, *“At last, I think up a truth, which is that illness is not the entirety of life.”*

For patients with SLE, chronic disease did not only represent a sad, depressing and hopelessness part of their lives, but offered the opportunity to pursue new paths. A3 mentioned that when she shifted her focus and applied to graduate school, she could temporarily forget her illness and turn her attention to the entrance examination. The meaning of the disease varied among the different participants, due to their personalities, as well as their family, social and economic backgrounds. The participants noted that their attitudes regarding the disease had changed over time, disease adaptation and living environment. As A3 commented, *“it is just like bridging for heart disease. There is one more thing in the heart. I feel that erythema is also a part of my body, so long as we get along well with each other”*. Therefore, sometimes illness represented an opportunity for personal growth [19].

A6 mentioned a comparison between SLE and vitiligo. A6 believed that *“from their appearance, SLE and vitiligo have obvious plaque. While the outside world has a higher acceptance of vitiligo, they might question whether SLE patients are contagious.”* A6 thought that the outside world did not know about their disease and when



people see patients' conditions, sometimes people worried about whether it is an infection. Many people had almost no understanding, which is the reason why SLE is misunderstood. The cultural environment could promote a greater understanding and acceptance of SLE.

When faced with adverse life experiences, the participants enjoyed sufficient ability, a stable mindset, and positive attitudes with regard to the future development of this little understood disease. From feelings of discomfort, anxiety and even irascibility during the early stage of the disease, acceptance and an ability to A3 "get along with the disease peacefully" ultimately seemed to prevail. Most of the participants' disease narratives broke with common ways of understanding time; disease and life events melded together. The significance of disease transferred from negativity into a new pursuit of life.

#### 4. Discussion

With a life-threatening disease or chronic illness, the process of psychological ownership is often instigated by an epiphany as a sudden revelation, turning point, significant life event, experience, critical juncture or realisation within a significant life event [20]. During the course of illness, the disease changed the patients' attitudes and understandings of illness, health, and social relations. The participants also learned to adjust their expectations and plans. As time passed and the patients learned to live with the disease, their interpretations of their situation shifted; they no longer viewed SLE with regard to biomedical attributes alone, but also as a complex interplay of social and cultural factors. These shifts imbued the disease with new meanings. That is, they would confront both the problem of treating the disease as well as the challenge of how to maintain and develop social relations. This problem could not be solved by medical treatment. Rather, it would need to be addressed by both patients and society. This study made several important contributions as mentioned below.

##### 4.1. Redefining disease

First, it provided a distinct approach to the way that disease is defined. The distinct interpretations of the same disease offered by different patients served to yield a more complete understanding of the disease. The disease is not limited to medical attributes, but also to the dynamic interplay of the emotions and experiences of the people who live with it. The impact of chronic diseases including SLE should be addressed together with the physical symptoms. Patients may come to acknowledge and accept SLE as the disease develops over time and also learn to control and manage it. They may experience new personal growth from having lived with the disease. Therefore, the emergence of chronic diseases should not be interpreted as a biographical disruption [9]; the trajectory of disease could result in a positive experience. Often, the depression, anxiety, or the "the encouragement of disease," during the early stage of illness represent a stage in an individual's experience of illness; they do not represent the entirety of the experience of the disease. The patient's description of the disease is also the description of their body. Although Latner and Stunkard had suggested that the negative effects of (visible) physical diseases and disabilities may have become stronger over time [21], the patients' narratives could turn hopeful in the future and reverse the meanings the disease had for them. As A5 noted, "Regular examinations could prevent other diseases." These findings support the claim that patients recovered some of their vibrancy when SLE symptoms were minimal. The women's lives became fuller, their bodies were at peace, life flourished, and experiences of movement and balance were intensified. The women almost forgot their illness [4].

##### 4.2. Re-examine the relationship between "disease", "body" and "self"

Secondly, this study aimed to improve understandings about chronic disease (especially for SLE patients), challenge stereotypes, and explore the impacts of chronic disease on the individuals through an examination of patients' daily life experiences. This study was conducted through observation and direct contact with SLE patients. The study design permitted an exploration of the impacts of chronic disease on the life course. The disruption highlights the resources (cognitive and material) available to individuals, modes of explanation for pain and suffering, continuities and discontinuities between professional and lay approaches, and the sources of variation in experiences. There has been much discussion about Bury's findings. The influence of chronic disease shifted the focus from the medical field to social life. There is a high probability of developing a chronic disease, and a majority of people live with chronic diseases for a long time. Often when individuals have discovered that they have a chronic disease, they pay more attention to their overall health, receive regular examinations to prevent other diseases, and make adjustments to their working lives. The occurrence of chronic disease often has prompted patients to make changes and integrate the disease into their daily lives.

As Faircloth, Boylstein, Rittman, Young, and Gubrium noted in studies on stroke patients, once other health concerns are taken into account, the illness in question could shift from being a disruption to becoming a part of one's ongoing health history [22]. The long-term nature of chronic diseases makes necessary an adaptation to the disturbances they provoke. The participants in this study responded by overcoming the tendency to treat the disease separately from their overall health. Therefore, the medicalization process—such as medication, follow-up, and recuperation—proved to have penetrated into their everyday lives. They faced the uncertainty and recurrence of the disease with adjustments in their living conditions and habits; daily life would revolve around changes in the manifestation of the disease and the disease progression would become one of the necessary part of their lives. Moreover, with the control of the disease condition, these individuals could re-examine the relationship between "disease", "body" and "self", and accept the existence of the disease or consider it as "reasonable existence" (A8). For the patients, mutual interactions and feedback from the external world—as opposed to the media used—were what enhanced social relationships. When dealing with chronic disease, there has existed a dynamic exchange between patients and doctors. The patients often recognized the authority and professionalism of the doctors. However, they also would make adjustments to the information they received. Many of the patients engaged in "deviant behavior" as they confronted the disease. For example, some patients continued to eat spicy foods, despite their understanding that those should be avoided. Patients tended to re-interpret the disease according to their environments, economic conditions, cultural concepts, habits, customs and beliefs. Disease patterns often have proven highly individualized; patients and doctors' understandings about treatment and recuperation frequently have been quite different. The participants in this study responded according to their own situations, making adjustments to their recuperation and the medicalization of their condition to the extent that they felt comfortable. As Ambrosio referred, although disruption and loss of balance could also take place, when patients achieve the new normal, they develop the attributes in a sense that makes them less vulnerable to any distressing factor than in false normality [23].

#### 4.3. Limitation and recommendations for further research

This study conducted in-depth interviews with nine SLE patients to understand their experiences of the disease and the corresponding impacts on their everyday life, but it also suffered from the following shortcomings: small sample size and lack of male interviewees. Therefore, for further research, the study sample size will be expanded and male patients will be actively sought to further comprehensively understand and observe the impacts of the disease on individuals. Moreover, whether there are differences between male and female patients after the disease will also be explored. In addition, our further research will continue to trace the previous interviewees in order to gain a more comprehensive understanding of the patients' everyday life.

#### 5. Conclusion

This current study has shown that people with SLE adjust their thinking about the disease based on personal feelings as well as experiences and pursue a dialogue on their illness based on the disease pattern unique to them. The meaning that disease had for the participants was not limited to negative connotations. Therefore, it is important to note that chronic diseases could have diverse sets of meanings in illness narratives. During an experience of illness, negative emotions—such as grief—comprise just one part of the entire process.

#### CRedit authorship contribution statement

**Zheng Huangfu:** Conceptualization, Data curation, Writing - original draft, Writing - review & editing.

#### Declaration of competing interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

#### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijnss.2020.05.006>.

#### References

- [1] Olesińska M, Saletta A. Quality of life in systemic lupus erythematosus and its measurement. *Reumatologia* 2018;56(1):45–54. <https://doi.org/10.5114/reum.2018.74750>.
- [2] Wang Z, Wang Y, Zhu R, et al. Long-term survival and death causes of systemic lupus erythematosus in China: a systemic review of observational studies. *Medicine* 2015;94(17). <https://doi.org/10.1097/MD.0000000000000794>.

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- [3] Jolly M, Pickard AS, Mikolaitis RA, et al. Body image in patients with systemic lupus erythematosus. *Int J Behav Med* 2012;19(2):157–64. <https://doi.org/10.1007/s12529-011-9154-9>.
- [4] Zhao Q, Chen H, Yan H, et al. The correlations of psychological status, quality of life, self-esteem, social support and body image disturbance in Chinese patients with Systemic Lupus Erythematosus. *Psychol Health Med* 2018;23(7):779–87. <https://doi.org/10.1080/13548506.2018.1434214>.
- [5] Larsen JL, Hall EOC, Jacobsen S, et al. The existential experience of everyday life with systemic lupus erythematosus. *J Adv Nurs* 2018;74(5):1170–9. <https://doi.org/10.1111/jan.13525>.
- [6] Hale ED, Trehan GJ, Norton Y, et al. 'Concealing the evidence': the importance of appearance concerns for patients with systemic lupus erythematosus. *Lupus* 2006;15(8):532–40. <https://doi.org/10.1191/0961203306lu2310xx>.
- [7] Karassa FB. Suicide attempts in patients with systemic lupus erythematosus. *Ann Rheum Dis* 2003;62(1):58–60. <https://doi.org/10.1136/ard.62.1.58>.
- [8] Svenaeus F. Illness as unhomelike being-in-the-world: heidegger and the phenomenology of medicine. *Med Healthc Philos* 2011;14(3):333–43. <https://doi.org/10.1007/s11019-010-9301-0>.
- [9] Bury M. Chronic illness as biographical disruption. *Sociol Health Illness* 1982;4(2):167–82. <https://doi.org/10.1111/1467-9566.ep11339939>.
- [10] Charmaz K. "Discovering" chronic illness: using grounded theory. *Sociol Health Illness* 1990;30(11):1161–72. [https://doi.org/10.1016/0277-9536\(90\)90256-R](https://doi.org/10.1016/0277-9536(90)90256-R).
- [11] Fiese BH, Bickman NL. Qualitative inquiry: an overview for pediatric psychology. *J Pediatr Psychol* 1998;23(2):79–86. <https://doi.org/10.1093/jpepsy/23.2.79>.
- [12] Kleinman A. *The illness narratives: suffering, healing and the human condition*. New York: Basic Books; 1988.
- [13] Davis EM. Risky business: medical discourse, breast cancer, and narrative. *Qual Health Res* 2008;18(1):65–76. <https://doi.org/10.1177/1049732307309002>.
- [14] Hochberg MC. Updating the American College of Rheumatology revised criteria for the classification of systemic lupus erythematosus. *Arthritis Rheum: Off. J. Am. College Rheumatol.* 1997;40(9):1725. <https://doi.org/10.1002/art.1780350502>.
- [15] World Medical Association. Declaration of Helsinki: ethical principles for medical research involving human subjects. <http://www.wma.net/en/30publications/10policies/b3/index.html>.
- [16] Emanuel EJ, Wendler D, Grady C. What makes clinical research ethical? *Jama* 2000;283(20):2701–11. <https://doi.org/10.1001/jama.283.20.2701>.
- [17] Hassanin AM, Ismail NN, el Guindi A, et al. The emotional burden of chronic skin disease dominates physical factors among women, adversely affecting quality of life and sexual function. *J Psychosom Res* 2018;115:53–7. <https://doi.org/10.1016/j.jpsychores.2018.10.011>.
- [18] McElhone K, Abbott J, Gray J, et al. Patient perspective of systemic lupus erythematosus in relation to health-related quality of life concepts: a qualitative study. *Lupus* 2010;19(14):1640–7. <https://doi.org/10.1177/0961203310378668>.
- [19] Wittmann L, Sensky T, Meder L, et al. Suffering and posttraumatic growth in women with systemic lupus erythematosus (SLE): a qualitative/quantitative case study. *Psychosomatics* 2009;50(4):362–74. <https://doi.org/10.1176/appi.psy.50.4.362>.
- [20] King G, Cathers T, Brown E, et al. Turning points and protective processes in the lives of people with chronic disabilities. *Qual Health Res* 2003;13(2):184–206. <https://doi.org/10.1177/1049732302239598>.
- [21] Latner JD, Stunkard AJ. Getting worse: the stigmatization of obese children. *Obes Res* 2003;11(3):452–6. <https://doi.org/10.1038/oby.2003.61>.
- [22] Faircloth CA, Boylstein C, Rittman M, et al. Sudden illness and biographical flow in narratives of stroke recovery. *Sociol Health Illness* 2004;26(2):242–61. <https://doi.org/10.1111/j.1467-9566.2004.00388.x>.
- [23] Ambrosio L, et al. Living with chronic illness in adults: a concept analysis. *J Clin Nurs* 2015;24(17–18):2357–67. <https://doi.org/10.1111/jocn.12827>.