Patient experiences of systemic lupus erythematosus: Findings from a systematic review, meta-summary and meta-synthesis

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TITLE PAGE

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Word count: 3890

No authors have any financial support or other benefits from commercial sources for the work reported on in the manuscript, or any other financial interests which could create a potential conflict of interest or the appearance of a conflict of interest with regard to the work.

ABSTRACT

Objective: To explore the experience of patients with systemic lupus erythematosus (SLE).

Methods: A systematic review of qualitative studies published in English in the past 10 years and identified through the PubMed, CINAHL, Scopus and Web of Science databases was performed following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. The methodological quality of each included study was assessed using the Critical Appraisal Screening Programme tool. Study findings were then subjected to a meta-summary and meta-synthesis.

Results: Twenty-six studies with a good overall methodological quality have been included, documenting the experience of 565 adult patients (95% women). A total of 17 codes emerged, summarising the life experience of SLE patients; the most and least frequent codes in the meta-summary were *'Feeling not as I usually do*' (69.2%) and *'Having wishes'* (7.7%), respectively. The codes were then categorised into five main themes, summarising the experience of living with SLE: (1) *'Experiencing waves of emotions due to the unpredictable nature of the*

disease'; (2) *'Trying to live an ordinary life'*; (3) *'Listening to and obeying the body's limitations'*; (4) *'Reviewing my life projects'*; and (5) *'Dealing with future uncertainties'*.

Conclusions: Several qualitative studies have been published to date using good methodological approaches. According to the findings, SLE negatively impacts patient experiences by affecting multiple dimensions of their daily lives, with fatigue and pain as the most frequent symptoms.

KEYWORDS

adult patient; chronic illness; meta-summary; meta-synthesis; qualitative research; rheumatology; systemic lupus erythematosus

SIGNIFICANCE AND INNOVATIONS

- This is the first systematic review including a meta-summary and meta-synthesis of qualitative studies regarding the experience of patients with systemic lupus erythematosus.
- Living with systemic lupus erythematosus is characterised by five themes: (1) *'Experiencing waves of emotions due to the unpredictable nature of the disease'*; (2) *'Trying to live an ordinary life'*; (3) *'Listening to and obeying the body's limitations'*; (4) *'Reviewing my life projects*; and (5) *'Dealing with future uncertainties'*.
- Systemic lupus erythematosus negatively impacts patient experiences by affecting multiple dimensions of their daily lives. In living with lupus, patients are required to change their life goals and to live with continuous uncertainty.
- Fatigue and pain still remain the primary unmet needs in the treatment of systemic lupus erythematosus.

INTRODUCTION

Systemic lupus erythematosus (SLE) is a severe autoimmune rheumatic disease with multisystemic, chronic and inflammatory characteristics (1,2,3). Incidence rates range from approximately 1 to 10 per 100,000 person-years, whereas prevalence is between 20 and 70 per 100,000 person-years (4,5). Moreover, SLE incidence has been reported as being higher in young women and in African Americans than in other demographics (1,6,7).

Some time prior to a diagnosis of SLE, a number of seemingly disconnected symptoms may be reported, such as fatigue, weight loss and unexplained fevers. The most commonly documented initial symptoms are arthritis, other musculoskeletal pain, and rashes (often associated with photosensitivity) (8). The disease symptoms may follow a fluctuating trend, with flares, relapses and remissions throughout life, and great variation between individuals and even over time within the same person (9,10).

Advances in clinical care have allowed most people with SLE to have a relatively normal life expectancy; however, its intrusive, fluctuating and multidimensional symptoms have been reported to affect their quality of life (QoL) (9). Patient experiences and coping strategies, as well as the degree of self-criticism and illness-related effects on interpersonal relationships with family, carers and with physicians, have also been reported to affect QoL (11,12). However, despite the relevance attributed to patient-reported outcomes (PROs), given their capacity to allow a full understanding of the patient experience and enhance symptom management and outcomes (13), no synthesis of the qualitative studies available describing the experiences of patients with SLE has been published to date. Understanding these experiences in depth, by summarising the evidence gathered in qualitative studies, may increase the capacity of health-care professionals to identify patient needs (14), develop better management options, and inform quality-of-care indicators (15). Filing in this gap was the main intention of this study.

MATERIALS AND METHODS

Study design. The following research question: 'What is the experience of patients with SLE?' was established according to the population, exposure and outcome framework (16). Thus, a systematic review of qualitative studies was performed (17,18).

Searching and retrieving literature. Two researchers independently conducted a systematic research of primary studies published up to July 2019 by accessing four databases: the CINAHL, MEDLINE, Scopus and Web of Science. The references of the included studies were also checked manually and an expert librarian supervised the entire process and independently performed the research, achieving the same outcomes. The following search terms were identified: 'systemic lupus erythematosus', 'qualitative research' and 'qualitative study' combined with the Boolean operator (AND). The inclusion criteria were: (a) primary studies written in English; (b) based on qualitative designs; (c) aimed at exploring the subjective experiences of adult patients regarding living with SLE; and (d) published between 2009 and 2019, thus reflecting the lived experience of patients with access to recent treatments. Studies not reporting patients' experience (19), that were quantitative in nature, concerning the paediatric population (age < 18 years) (20), or including patients without a defined diagnosis of SLE (21) according to the American College of Rheumatology, were excluded (Figure 1).

Quality appraisal. The Critical Appraisal Screening Programme (CASP) (22) was used to evaluate the methodological quality of the included studies. The appraisal was conducted by two reviewers, independently (Supplementary Table 1).

Analysis, synthesis and integration of findings: An inductive analysis (18, 23) was performed by (a) extracting study findings and separating them from other elements of each manuscript; (b) editing the findings extracted; (c) grouping them in common domains; (d) abstracting them as codes; and (e) calculating the manifest frequency and intensity of the effect size. Codes were grouped and categorised into themes by replication or confirmation, extension or refuting each other, based on their similarities (18) (Supplementary Table 2). Code frequency was then computed by taking the number of studies containing the same code and dividing this number by the total number of studies; code intensity was instead derived by dividing the number of codes contained in one given study by the total number of findings across all studies (24). Then, a conceptual diagram representing the experience of SLE patients was developed.

RESULTS

Studies. A total of 26 studies emerged (Supplementary Table 3), with 11 conducted in the US (25–35). Overall, we included 565 patients reporting their own experience, 537 of whom (95%) were women. The average age of patients at the time of reporting was 43.5 years (range:

18–80). The ethnicity of the sample varied, with a majority of African-American people (25,27) and black people (29,31,34,43). White, Caucasian and Asian minorities were also represented (2,3,32,36).

The most frequently reported symptom was skin rash (38,47), followed by musculoskeletal deficits (2,4), pain and fatigue (3,47). Where reported, disease duration ranged from 1 year (36,42,44,48) to 45 years (4).

The SLE patients' experiences were mainly explored using qualitative (12 studies, e.g., 2,27) and interpretative (5 studies, e.g., 32,42) phenomenological approaches. Data was collected using semi-structured or open interviews and focus groups conducted in various settings (e.g., health-care facilities) (36,38). In the CASP evaluation, all studies showed a good methodological quality (all total scores > 7.5), with item no. 6, '*Has the relationship between researchers and participants been adequately considered?*', most often not reported or reported unclearly.

Meta-summary. A total of 17 codes emerged: two studies (44,46) presented the highest code intensity (64.7%) and two (5,45) the lowest (5.9%) (Table 1 and Table 2). Moreover, the most frequent code across studies was *'Feeling not as I usually do'* (69.2%) followed by *'Being in a relationship with a health-care professional means being compliant*' (53.8%) (Table 1 and Table 2). Conversely, the least frequent code was *'Having wishes'* (7.7%).

Meta-synthesis. The 17 codes that emerged were categorised into five themes (Figure 2).

Theme 1. '*Experiencing waves of emotions due to the unpredictable nature of the disease':* SLE is characterised by active and less active disease phases, attacking the skin and vital organs in unpredictable flares and remissions throughout life. Patients live *'Inside of these waves'*, where illness, function and emotional interactions generate an *'Ever-shifting picture'*. Therefore, the existential condition of living with SLE is interpreted through the metaphor of *'Moving with the waves of SLE'* (4). On the one hand, the fluctuating nature of SLE limits several aspects of patients' daily life, but on the other hand, it gives hope to patients, which is why the moments of good health seemed to be vital, as *'You can forget how it is (lupus) and other things fill up the day'*. At the same time, *'If you suddenly get something, everything is at a standstill again and it takes time before you resurface'* (4). Also, SLE is a *'Dominant and unpredictable force, infiltrating everyday life'* (4) and intruding upon thinking, relationships and social planning. A broad range of negative emotions has been expressed by patients in available studies, such as anger, frustration, resentment, anxiety, helplessness, depression and poor self-esteem (e.g., 42):

'You cry and you have different mood swings. You're depressed. You feel worthless. You feel like nobody cares for you' (47). Working seemed to distract patients from these negative feelings, because *'when you're very happy, you don't notice the negative influence of the illness'* (46). Furthermore, in several studies (3,29,42,44,46), the feeling of uncertainty is emphasised because *'You don't know if you will be able to be so lively today, but you'll be having a flare-up next week'* (39), showing the unpredictability of the disease.

Theme 2: '*Trying to live an ordinary life':* Symptoms of SLE, especially pain and fatigue, have been reported to limit or prevent activities such as household chores, gardening, cooking, and self-care: *'You can't go anywhere; you can't go to the store; you can't play with your children and you can't cook sometimes and you can't really do what you're supposed to do, the daily chores you want to do and you can't really do it'* (27). Therefore, sometimes patients are forced to get help from others or push themselves to complete activities (47). While experiencing these different limitations, patients wish to live normal lives, without being controlled by symptoms (36). However, to deal with everyday life, patients need family support that is unconditional and 'always there'. Family appeared to offer a sense of security in the context of an unpredictable illness, sometimes over and above other relationships: *'When I'm really bad, none of my friends see me ... my family do'* (46). The support of family and friends is essential, but often patients feel misunderstood because *'I am also my illness, but I am not only my illness'* (2). Moreover, patients reported a distorted view of themselves as a consequence of the fear of being negatively judged by others. Expectations of negative judgement seemed to contribute to worries about social interactions, and social withdrawal was common in these people (46): *'Isolation, friendship, relationships, even family, because you don't want to talk about it because there is a sense of shame…and something is wrong and people don't understand, and so it's isolating sometimes…'* (32).

Theme 3: '*Listening to and obeying the body's limitations':* Despite attempts to live an ordinary life, patients are forced to pay attention to their symptoms (e.g. fatigue, pain, insomnia). In particular, fatigue is experienced both as a bodily sensation and as a combination of emotions: *'Fatigue means to me a lack of energy, exhaustion, tiredness, a lack of focus, which means you're not alert, just subdued'* (27). The symptoms of the disease are associated with visible signs, such as weight gain, skin manifestations and alopecia, which can lead to a loss of personal identity: *'I'm so embarrassed about how my body looks. I'm just not myself and people who look at me don't*

know who I really am inside. They see a sick, bloated woman and it just makes me feel so discouraged' (30). Bodily limitations have been reported to impact on physical functionality, but also other dimensions, such as career development, since many patients *'have to take time off work…because they are not feeling well'* (47). Family planning may be affected, because *'a third of women with lupus who become pregnant have a miscarriage, which is obviously another concern'* (44).

Women have been reported to experience a loss of personal identity, losing the role of daughter, wife and mother (29) due to the symptoms; furthermore, the disease limits sexual identity and the development of an intimate relationship with a partner. Patients have been documented to be unable to plan their future due to the uncertainties of their bodies. To face this serious limitation, they planned or prioritised their everyday life by establishing a strategy to seize the moment and to be prepared to live each moment of strength (40): *'I follow a regular regime when I come home. After work, it's home, then food, followed by a rest. If I have more energy, then other things come afterwards'* (36).

However, as reported in some studies (36–38), during the illness trajectory, patients have been reported to accept their body's limitations, because they have learnt that adapting reality to their own limitations is more effective than continuing to fight the disease.

Theme 4: *'Reviewing my life projects':* Patients have been documented to initiate a process of revision of their life plans only after receiving the diagnosis of SLE. Studies reported that patients experienced a long '*liminal state'* marked by a protracted period of unexplained symptoms while searching for a diagnosis (e.g. 28). Receiving the diagnosis *'was actually a relief'* (28); patients have been reported to immediately feel freed from the stigma once given *'a legitimate name for all the trouble'* (28).

In reviewing their life goals, patients relied on their personal resources, including mental struggle. They learned how to plan and prioritise everyday life to be able to complete all daily tasks, by cultivating spirituality and participating in activities that increase inner well-being, including yoga, physical and social activities (30,40,46). Furthermore, patients have been reported to depend on family, medical and health-care professionals, and hospital support (44).

Medications have been reported to lead to patients experiencing mixed feelings. Medications allowed them to feel healthy, but at the same time, medications may cause a series of

side effects (e.g. weight gain, skin lesions), affecting patients' body image. This impact has been expressed as looking in the mirror and not recognising the person reflected: *'Uh, the man in the moon face. You don't recognize yourself…'* (43). Patients reported negotiating their role at work in order to remain employed: such modifications included working part-time and looking for work closer to home (37). However, unemployment rates have been reported to be high, due to the physical limitations and the multiple hospital visits and admissions (48). Therefore, many patients experienced financial difficulties due to unemployment and the continuous increase in expenses to afford adequate care (35).

Theme 5: '*Dealing future uncertainties':* Patients considered it to be important that clinicians were able to give clear and accurate information regarding their health, the treatment options and the potential side effects of the medications (43). They reported the desire to be informed and participate in the decisions, manifesting their capacity to express self-determination over the limitations imposed by the disease: *'It's no-good saying "no", you need to do a blood test. I want to know why the gamma globulins, you know, why are they high, how is that going to affect me'* (44).

Those patients who did not have a positive relationship with physicians and complained about the lack of information received also report low medication adherence (38), in part a consequence of the *'horrible'* side effects (43,48): *'I used to stop medication from May or June onwards. It was to get slimmer to go to the beach'* (38). Moreover, a lack of understanding about the disease and medication could result in patients taking greater interest in alternative therapies or relying on their faith, which may have an impact on adherence (41).

The complexity of the disease, as experienced by patients, also affects their wishes. The apathy experienced has been reported to result in psychological symptoms, including anxiety, depression and mood disorders (3,27,30,31,40,42,47); consequently, the capacity to identify long-term wishes is also threatened. They experienced uncertainty about the fulfilment of their desires: maintaining daily activities, minimising the medication side effects, preventing future organ damage and finding a cure (25) are their major wishes. Having support in the case of pregnancy, which is often complicated by the disease (38,42,44), also emerged as a major wish.

Patients have been reported to be afraid of not having a voice in a misinformed society, where some believe that *'I have HIV'* (48). They called for greater public awareness of SLE and sought to disseminate accurate information to family, friends and acquaintances (48).

DISCUSSION

Despite the many high-quality qualitative studies that have been produced on this topic, to our best knowledge, this is the first systematic review providing a meta-summary and a meta-synthesis of these studies on the experience of patients with SLE. This is of particular relevance since improvement in PROs is becoming a critical goal for new treatments in rheumatic musculoskeletal diseases, and prioritisation of the unmet needs in this field may be of value for future research.

Studies. A total of 26 studies were included, suggesting that ample attention has been given to the subjective experience of these patients in the last 10 years, mostly in the US, in accordance with the prevalence of the disease (6). Studies involved a large majority of adult females with different clinical conditions and different disease trajectories, ranging from just diagnosed (e.g. one year) (42) to long-lasting (45 years) (4). This suggests that the findings of this review may reflect the disease experience of the overall population with SLE well.

Studies involving single patients or patient groups used different qualitative approaches: although all were based on open-ended or semi-structured interviews (except for 28). Some were administered more than once (3,4,25,34,44), thus ensuring the reliability of the data collected (49). However, a large number of studies did not report the year of data collection (e.g. 37, 34), which is important in the context of SLE, since novel treatments (e.g. belimumab) have been introduced over the years (50).

The CASP tool (21) confirmed the quality of the included studies. Most of the inadequacy is due to lack of clarity of the information reported, which might be addressed in the future by using established guidelines in qualitative studies (e.g. 52).

Meta-summary. In terms of intensity, two studies (44,46) provided the highest level and two (5,45) the lowest. Similarities in the findings reported across studies (e.g. 3,27) included reporting fatigue and pain as the most frequent symptoms experienced by patients, affecting body image, functioning and self-esteem, and impacting on interpersonal, familial and romantic relationships. These factors have generated the code '*Feeling not as I used to'*. This code was also the most frequent across studies, reaching an intensity of 69.2%, suggesting that future trials on SLE and novel treatments should prioritise the measurement of these aspects. The most intense codes (≥ 50%) were *'Being in a relationship with a health-care professional means being*

compliant' and *'Relying on family carers' support'*. On the other hand, *'Having wishes'* was the least intense code across studies, reaching an intensity of 7.7%; the unpredictable course of the disease makes patients with SLE unable to plan their long-term goals, thus imposing the need to live life on a daily basis, in the present moment. In other words, SLE preventing patients from having wishes is a double-edged sword, as having wishes should be an option for all people, but on the other hand, living in the moment may be best for them due to the complexity of living with a chronic disease such as lupus.

Meta-synthesis. The five themes that emerged underline how SLE limits the QoL of patients in multiple dimensions, including socially. Moreover, it has emerged that these themes interact with each other, suggesting that SLE is a complex disease to live with.

The first theme, namely: *'Experiencing waves of emotions due to the unpredictable nature of the disease'*, reflects the unpredictable course of the disease and the fact that patients must navigate the variable presence and absence of SLE (4). Illness uncertainty is a salient issue for many who have been diagnosed with chronic illnesses, above all rheumatic disease; for example, patients with fibromyalgia have described uncertainty as a cognitive stressor and a sense of loss of control over time (53). For these reasons, it is useful to teach patients how to cope better with both the uncertainty and unpredictability of their illness through mindfulness approaches focusing on concepts such as acceptance and living in the moment (54,55). When patients are engaged in different activities, such as creating something or socialising, they felt that they *'Moved into the waves of SLE'* and those moments appear to be vital for their wellbeing.

The second theme: *'Trying to live an ordinary life'*, which also contains the code with the highest intensity, *'Feeling not as I usually do'*, highlights that patients experienced limitations in everyday life activities, especially due to pain and fatigue (56). Fatigue is a common clinical symptom affecting almost all patients with SLE, while pain is the most common symptom of rheumatic diseases (57). Psychoeducational, stress reduction, cognitive behavioural and antidepressant therapy in patients with autoimmune disease have been shown to reduce fatigue, psychological distress and pain (58); these strategies could also be useful among patients with SLE. Moreover, a self-management programme can help patients to control the physical and emotional instability associated with SLE, and might help health-care professionals to be more effective in their care (59).

The third theme that emerged: *'Listening to and obeying the body's limitations'*, highlights the importance of listening to the body and distributing energy reserves throughout the day. In this phase, it is essential for patients to accept the illness as a part of their life. However, some patients preferred to fight the disease instead of adapting to it, despite no positive advantage to their life. Helping patients to create a daily activity plan by assigning priorities to each activity and uniformly distributing the most tiring tasks throughout the day might be useful (60). Preventing exacerbations by providing emotional support and training to both individuals and their families using a holistic approach may also be fundamental (57).

Through listening to and obeying the body's limitations, it is possible to move into a new phase, *'Reviewing my life projects'*. In this step, patients need to mobilise psychological, physical, social and/or material resources (60). The resource perceived as the most important by them is the support of the family; for this reason, *'Relying on family and professional carers' support'* is the second-highest intensity code that emerged within this theme. Family support appeared to offer a sense of security in the context of an uncertain illness, along with being viewed as unconditional and 'always there', although sometimes patients felt misunderstood or not believed even by loved ones (44,46). Patients should be supported in learning how to readjust their life plans by accepting the help of others, discovering personal resources, and adapting each activity (especially their job) to their health requirements. Only when patients have reviewed their life goals, can they try to live an ordinary life (Theme 2).

The last theme, *'Dealing future uncertainties'*, contains three significant codes. The first, *'Being in a relationship with a health-care professional means being compliant'*, is the second-highest intensity code and underlines the importance of developing a physician-patient relationship to maintain adherence to medical care and consequently a good QoL. Several studies have highlighted the importance of a good relationship to promote adherence to medication and increase self-management (e.g. 28,38,41,43,44,45). The higher the quality of the patient-physician relationship, the better the patient outcomes will be (61). Non-adherence to treatment, non-attendance of clinics and reassurance-seeking were suggested by health-care professionals to have an impact on illness outcomes, health-care costs and on the doctor-patient relationship (44). Often patients felt mistrusted by clinicians; for this reason, education, support and understanding from the health-care team are crucial in order to ensure that patient choices are respected (43).

The second code: *'Having wishes'*, was the least intense, as the unpredictable disease trajectory limits patients' expression of long-term desires. Psychological support such as counselling and psychoeducational interventions have been reported to have a potential value as adjunctive treatments for SLE (62). The last code *'Having a voice in society'*, reported the lowest intensity (23%). SLE patients feel themselves to be part of an uninformed population and demand greater public awareness of the nature of the disease and the problems it causes in everyday life (46). Family, friends and employers often do not understand the fluctuating nature of SLE, leading to isolation (63). To prevent loneliness, attention should be given to increasing social support and awareness (64).

Limitations. A systematic approach has been used; however, some studies may have been missed. Moreover, studies conducted in different countries, with different languages and cultures, have been included. The translation process might have changed the meaning of the patient experiences, and the influence of the culture has not been considered.

Conclusions. Several qualitative studies have been published in this field to date using good methodological approaches. According to the findings, SLE negatively impacts patient experiences by affecting multiple dimensions of their daily lives, with fatigue and pain being the most frequent symptoms. In living with SLE, patients are required to change their life goals and to live in a sort of continuous uncertainty. Understanding in depth the multidimensional implications of SLE in the short and long term might help health professionals to tailor their approach in each stage of the disease trajectory, through an effective relationship. Moreover, including these aspects in future trials aimed at testing the effectiveness of novel medications is highly recommended.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication.

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Table 1. Meta-summary (24): code intensity in the included studies

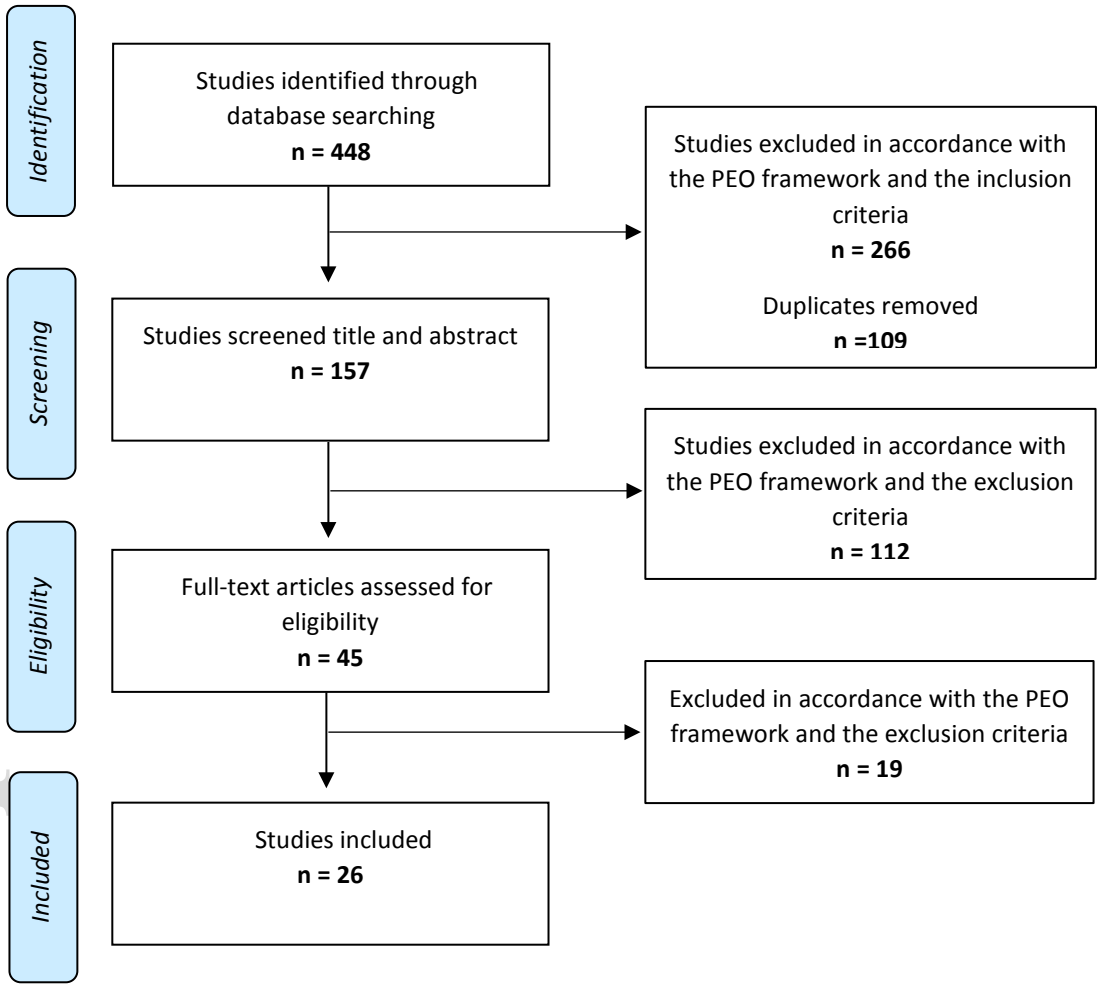
Studies	Codes (n = 17)	Intensity (%)
Cleanthous et al., 2013 (44)	C2, C4, C5, C7, C8, C9, C10, C11, C13, C14, C15	64.7
Rutter and Kiemle, 2015 (46)	C1, C3, C4, C5, C6, C7, C8, C9, C10, C11, C12	64.7
Farinha et al., 2017 (38)	C1, C2, C4, C5, C6, C9, C10, C16, C17	52.9
Phuti et al., 2019 (48)	C1, C2, C3, C4, C5, C6, C8, C9, C10	52.9
Beckerman, 2011 (30)	C1, C2, C3, C4, C5, C6, C8, C15	47.0
McElhone et al., 2010 (42)	C1, C2, C3, C4, C6, C7, C9, C11	47.0
Pettersson et al., 2010 (40)	C1, C3, C4, C5, C6, C8, C11, C12	47.0
Mattsson et al., 2012 (39)	C1, C2, C3, C4, C7, C8, C14	41.2
Robinson et al., 2010 (32)	C1, C4, C5, C6, C7, C9, C10	41.2
Connolly et al., 2014 (37)	C1, C2, C4, C11, C14, C16	35.3
Woods, 2010 (31)	C1, C5, C6, C8, C11, C14	35.3
Kier et al., 2016 (36)	C1, C11, C12, C13, C14, C16	35.3
Williams et al., 2017 (33)	C1, C2, C6, C7, C10, C13	35.2
Mendelson, 2009 (28)	C2, C3, C7, C9, C13	29.4
Gallop et al., 2012 (47)	C1, C4, C5, C6, C10	29.4
Sterling et al., 2014 (27)	C1, C4, C5, C6, C10	29.4
Faith et al., 2018 (34)	C1, C5, C8, C12	23.5
Miles, 2011 (29)	C7, C9, C12, C15	23.5
Williams et al., 2015 (35)	C1, C2, C3, C15	23.5
Larsen et al., 2018 (4)	C1, C2, C7	17.6
Ng et al., 2018 (25)	C2, C8, C17	17.6
Hale et al., 2015 (43)	C1, C2, C13	17.6
Kumar et al., 2011 (41)	C2, C12	11.8
Yelin et al., 2019 (26)	C3, C15	11.8
Chambers et al., 2009 (45)	C2	5.9
Mazzoni and Cicognani, 2014 (5)	C5	5.9

C1 = Feeling not as I usually do; C2 = Being in a relationship with a health-care professional means being compliant; C3 = Relying on family and professional carers' support; C4 = Negotiating a meaningful occupation; C5 = Experiencing paradoxes in family and social relationships; C6 = An ever-shifting picture: illness. function and emotional interactions; C7 = Being inside of the waves; C8 = Relying on personal resources; C9 = Living an assault of my identity; C10 = Living limitations in daily life; C11 = Being limited in planning the future; C12 = Having a voice in the society; C13 = Having (finally) a diagnosis; C14 = Accepting being in need of help; C15 = Coping with the financial strain, C16 = Initiating the road to acceptance; C17 = Having wishes.

Table 2. Meta-summary of codes (24): frequency across studies

Codes	Studies (n = 26)	Frequency (%)
Feeling not as I usually do	(4,27,30,31,32,33,34,35,36,37,38,39,40,42,43,46,47,48)	69.2
Being in a relationship with a health-care professional means being compliant	(25,28,30,33,35,37,38,39,41,42,43,44,45,48)	53.8
Relying on family and professional carers' support	(4,26,28,30,34,35,37,39,40,42,44,46,48)	50.0
Negotiating a meaningful occupation	(27,30,32,37,38,39,40,42,44,46,47,48)	46.1
Experiencing paradoxes in family and social relationships	(5,27,28,31,32,34,38,40,44,46,47,48)	46.1
An ever-shifting picture: illness, function and emotional interactions	(27,30,31,32,33,38,40,42,46,47,48)	42.3
Being inside of the waves	(4,28,29,32,33,39,42,44,46)	34.6
Relying on personal resources	(25,30,31,34,39,40,44,46,48)	34.6
Living an assault of my identity	(28,29,32,38,42,44,46,48)	30.8
Living limitations in daily life	(27,32,33,38,44,46,47,48)	30.8
Being limited in planning the future	(31,36,37,40,42,44,46)	26.9
Having a voice in the society	(29,34,36,40,41,46)	23.0
Having (finally) a diagnosis	(28,33,36,43,44)	19.2
Accepting being in need of help	(31,36,37,39,44)	19.2
Coping with the financial strain	(26,29,30,35,44)	19.2
Initiating the road to acceptance	(36,37,38)	11.5
Having wishes	(25,38)	7.7

Figure 1 PRISMA flow diagram for research strategy and study selection and inclusion (16,17,18).



CINAHL = Cumulative Index to Nursing and Allied Health Literature; n = number; PEO = Population, Exposure, Outcome; PRISMA= Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

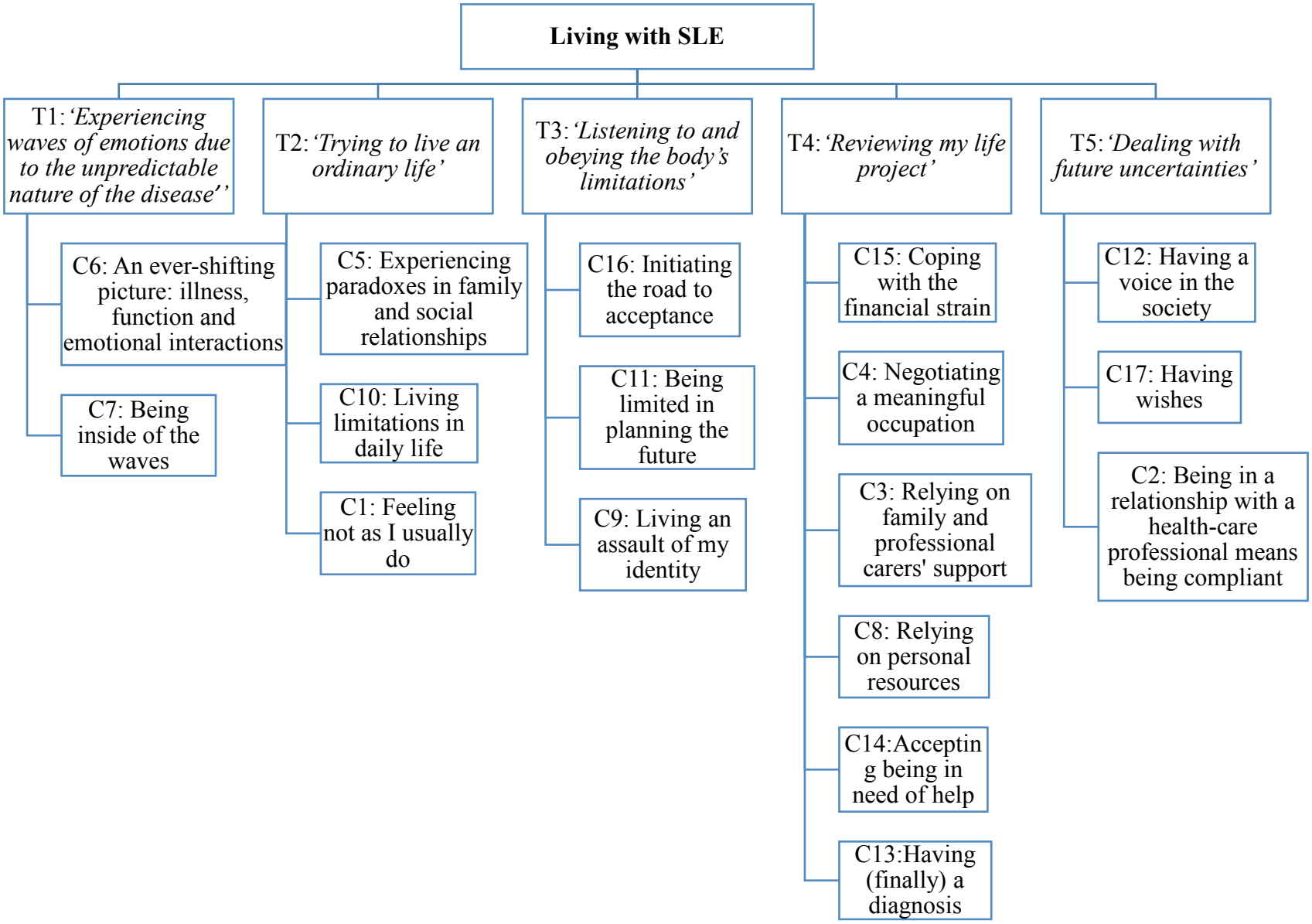


Figure 2 Living with SLE as experienced by patients: themes and codes.

C = CODE, C1 = Code number, SLE = systemic lupus erythematosus, T = Theme, T1 = Theme 1.