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Tailored Personas for Self-Management in Young and Middle-Aged Patients with Systemic Lupus Erythematosus: A Qualitative Study

Jiaying Chen
Third Affiliated Hospital of Southern Medical University
Long Zhang
Southern Medical University
Zhaorong Huang
Third Affiliated Hospital of Southern Medical University
Liuyuan Zhang
Southern Medical University
Yi He
Third Affiliated Hospital of Southern Medical University
Erwei Sun
Third Affiliated Hospital of Southern Medical University
Jiali Chen
chenjialibella@163.com

Third Affiliated Hospital of Southern Medical University

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Abstract

Aim

To explore the heterogeneity of self-management experiences among young and middle-aged systemic lupus erythematosus (SLE) patients, identify distinct patient personas based on their self-management behaviors, barriers, and needs, and provide a theoretical basis for personalized intervention strategies.

Methods

A qualitative descriptive study was conducted from November 2023 to February 2024 in the Department of Rheumatology and Immunology of a tertiary A general hospital. Purposive sampling with maximum variation was used to recruit 21 young and middle-aged SLE patients. Semi-structured in-depth interviews were conducted to collect data on self-management experiences, barriers, and needs. NVivo 12 software was used for data management, and content analysis was applied to extract core labels, construct dimensional models, and develop patient personas.

Results

A total of 21 SLE patients were enrolled in the study. Three key dimensions for constructing personas were identified: self-management characteristics, barriers, and needs. Five distinct patient personas were developed: (1) Knowledge-Deficient and Passive Managers, (2) Role-Overloaded and Conflict-Prone Managers, (3) Risk-Aware and Motivated Managers, (4) Support-Dependent and Collaborative Managers, (5) Misconceived and Behaviorally Deviant Managers. Each persona exhibits unique characteristics in disease knowledge, self-management skills, motivation, social support, and social role responsibilities.

Conclusions

The heterogeneity of self-management behaviors among young and middle-aged SLE patients is significant, and tailored interventions based on patient personas are essential to improve self-management effectiveness. Healthcare providers should develop personalized strategies targeting the specific needs and barriers of each persona to enhance disease control and quality of life for SLE patients.

1. Background

Systemic lupus erythematosus (SLE) is a chronic autoimmune inflammatory disease characterized by the production of autoantibodies, the formation of immune complexes and co-existance of multiple organ disorders [1]. The global prevalence of SLE is 168.5 (13 to 7,713.5) per 100,000 individuals and increases gradually over time [2, 3]. And the incidence rate of SLE has increased rapidly in recent years,

especially in young and middle-aged women[4]. SLE patients may perceive a variety of disease manifestations varying from mild issues with joints and skin to severe comorbidities affecting the kidneys, blood system, or central nervous system, which can seriously reduce their quality of life, impose a huge financial burden and psychological stress, and even result in death[5–7]. Despite advancements in therapy, patients often experience disease flares of varying severity [8]. As SLE predominantly affects women of young and middle age, this population group facing occupational responsibilities, family care-giving and reproductive planning, which can substantially impede disease management[9]. Although the age gap among SLE patients is smaller than that observed in other diseases, the patients exhibit significant heterogeneity in disease management behaviors, perceived barriers, available resources and support needs. Besides, the existing research has typically described the common and general SLE disease management recommendations, without systematically characterizing the subgroup variation [10]. The existence of this phenomenon may ignore sub-group difference, leading to disease exacerbation or flare.

Self-management refers to a person's capacity to handle the symptoms, treatments, physical and psychosocial effects, as well as the lifestyle adjustments required when coping with chronic illnesses [11]. The available evidence increasingly suggests that self-management has positive effects on alleviating adverse symptoms, relieving negative emotions and preventing flares in SLE patients. However, recent studies have shown that the self-management level of SLE patients is relatively low, and a large proportion of patients reported that they lack SLE self-management knowledge, skills, or confidence [12]. Additionally, the guidelines also emphasize that healthcare professionals should increase awareness of self-management for SLE patients [13]. Therefore, it is necessary to explore the factors that affect the implementation of self-management strategies from the patients’ perspective in order to develop targeted interventions, especially for young and middle-aged SLE patients, who are prone to multiple pressures that may hinder disease management [14].

Under the framework of precision nursing, constructing tailored patient personas based on individual characteristics has emerged as a promising approach to address heterogeneity in chronic disease management [15]. Patient personas are archetypal representations of subgroups with shared characteristics, needs, and challenges, enabling healthcare providers to design targeted interventions [16]. This approach has been successfully applied in home-based cardiac rehabilitation and other chronic disease settings, improving patient adherence and rehabilitation outcomes [17]. However, few studies have explored the heterogeneity of self-management in young and middle-aged SLE patients or developed tailored personas to guide personalized care.

Therefore, this study aimed to explore the self-management experiences of young and middle-aged SLE patients through qualitative interviews, identify distinct patient personas, and describe their unique characteristics, barriers, and needs. The findings provide a basis for developing precise self-management interventions that address the heterogeneous needs of this population, ultimately improving disease control and quality of life.

2. Methods

2.1. Study Design

A qualitative descriptive design was adopted because it allowed for the comprehensive exploration of participants' subjective experiences and perceptions, keeping the analysis close to the data and participants' own language, without imposing a predefined theoretical framework. Semi-structured interviews were conducted to facilitate flexible and focused discussions on participants' self-management experiences. The study was reported in accordance with the Standards for Reporting Qualitative Research (SRQR) [18].

2.2. Setting and Recruitment

Participants were recruited from the Department of Rheumatology and Immunology of a tertiary general hospital from November 2023 to February 2024. Purposive sampling with maximum variation was used to ensure diversity in age, gender, education level, disease duration, marital status, and employment status, thereby capturing a wide range of self-management experiences.

Inclusion criteria were: (1) meeting the 2019 EULAR/ACR classification criteria for SLE [19]; (2) aged 18–59 years; (3) conscious with no cognitive or communication impairments; (4) willing to participate and provide informed consent. Exclusion criteria were: (1) concurrent cancer or other severe systemic dysfunction; (2) history of psychiatric disease. The sample size was determined by data saturation, defined as no new themes emerging from three consecutive interviews [20]. A total of 21 patients were included in the study.

2.3. Data Collection

Eligible participants were recruited from the rheumatology and immunology department according to the inclusion criteria. Prior to interviews, a trained qualitative researcher explained the study's purpose, significance, and procedures to the participants and obtained the written informed consent. All interviews were conducted in a private and quiet meeting room to ensure confidentiality and minimize external interruptions. A semi-structured interview was used to facilitate face-to-face in-depth interviews. The conversation was recorded with a digital audio recorder, and nonverbal responses (e.g., facial expressions, body language) were documented. The interviewer should avoid leading questions or suggestive hints, and encourage participants to freely express their opinions. All interviews were audio-recorded and transcribed verbatim, with an average interview duration of 23 minutes. Participants also completed a brief demographic questionnaire including gender, age, educational level, marital status and employment status. Data collection continued until saturation was reached, defined as the point at which no new meaningful information emerged from subsequent interviews [21].

2.3.1. Interview guide

The preliminary semi-structured interview guide was developed through literature review based on the study objectives and discussion among the research team. Two participants completed pre-interviews using the preliminary guide. The guide was then refined according to the participants' feedback to ensure clarity, comprehensibility, and applicability. Core interview questions were as follows: (1) What is your understanding about self-management of SLE, and how do you usually manage it in daily life? (2) How do you evaluate your self-management level, and what additional knowledge do you consider necessary? (3) What factors hinder your implementation of self-management practices? (4) What factors facilitate your implementation of self-management practices? (5) How do people influence you during the process of the disease management? (6) What support do you expect from healthcare professionals?

2.3.2. Research team

The research team consisted of two experienced clinical experts and two nursing graduate students. The design of the study was discussed and approved by all the researchers. Data analysis were mainly conducted by two nursing graduate students. To avoid research bias, a nursing graduate student is responsible for the whole interview. Besides, any ambiguous analysis results were supervised and adjusted by the rheumatologist. All team members had experience in rheumatology practice and were trained in qualitative research to ensure the research rigor and scientific validity.

2.4. Data Analysis

The researchers transcribed the recorded materials into text within 24 hours after the interviews, and the results were presented anonymously by codes. The NVivo 12 software was used to analyze. Content analysis was applied to identify core themes and construct patient personas [22]. During the analysis process, two researchers analyze the interview data, including repeatedly reading the interview transcripts, identifying meaningful statements, coding recurring ideas, aggregating and forming core themes of participant self-management behaviors, defining and fully describing the themes, and extracting the theme to form the basic dimensions of patient persons label to describe the behaviors and needs of participants.

The patient features were extracted manually by integrating the identified themes, the researchers' disciplinary expertise and in-depth understanding based on the established dimensions. After persona construction, the analysis results were returned to the participants for checking to ensure that the personas accurately and authentically reflected patients' characteristics and experiences. To visually present the differences in self-management in SLE patients, the character images were drawn based on manually extracted character feature labels. If any disagreements existed, the results were discussed and adjusted by the research members.

2.5. Rigor

To ensure methodological rigor, critical quality control was implemented throughout the study process. First, the study protocol was developed based on prior literature review, group discussion and pre-interview to ensure clarity and comprehensibility. Second, during interviews, all recording was recorded

using audio devices and non-verbal behaviors of participants were also documented. Recordings were transcribed and preliminarily organized within 24 hours following each interview. Subsequently, the participants were contacted to verify the accuracy of the content, thereby enhancing the reliability of research. Additionally, all researchers ensured they had no relationship with participants, and the research members maintained a neutral stance throughout data collection and analysis. Finally, all study procedures including interview guides, transcribed texts, and analytical steps were documented, ensuring the research traceability. The research report adhered to qualitative research reporting standards [18].

3. Results

3.1. Demographic Characteristics of Participants

A total of 21 young and middle-aged SLE patients were interviewed, including 18 females (85.7%) and 3 males (14.3%). The age ranged from 20 to 59 years, with an average age of 32 years, and the disease duration ranged from 0.25 to 13 years, with an average duration of 5 years. Regarding education level, 3 patients (14.3%) had primary school education or below, 9 (42.9%) had secondary education, and 9 (42.9%) had college education or above. Most participants were married (76.2%) and employed (57.1%). Detailed demographic information is shown in Table 1.

Table 1
Demographic characteristics of the participants.

ID	Gender	Age (years)	Education level	Marital status	Employment status	Duration (years)	Disease activity
1	Female	44	Primary school	Married	Employed	5	Moderate
2	Female	56	Middle school	Married	Retired	5	Mild
3	Female	30	College	Married	Employed	9	Mild
4	Female	27	College	Unmarried	Employed	5	Severe
5	Male	34	Middle school	Married	Unemployed	0.5	Severe
6	Male	31	Middle school	Married	Employed	7	Mild
7	Female	20	Middle school	Unmarried	Employed	2	Mild
8	Female	21	College	Unmarried	Student	2	Mild
9	Female	28	College	Unmarried	Employed	7	Mild
10	Female	36	Middle school	Married	Employed	10	Severe
11	Female	59	Middle school	Married	Employed	13	Mild
12	Female	23	College	Unmarried	Student	2	Severe
13	Female	30	Middle school	Married	Employed	12	Mild
14	Female	56	Middle school	Married	Retired	0.25	Moderate
15	Female	23	Middle school	Married	Employed	0.25	Mild
16	Male	24	College	Unmarried	Employed	2	Moderate
17	Female	30	Middle school	Married	Employed	7	Severe
18	Female	28	College	Married	Employed	3	Moderate
19	Female	27	College	Unmarried	Employed	2	Severe
20	Female	25	Middle school	Married	Unemployed	9	Severe

ID	Gender	Age (years)	Education level	Marital status	Employment status	Duration (years)	Disease activity
21	Female	31	College	Unmarried	Employed	4	Mild

3.2. Tailored Personas for Self-Management in Young and Middle-Aged SLE Patients

Five distinct patient personas were identified based on self-management characteristics, barriers, and needs (Table 2). Each persona represents a unique subgroup with specific challenges and intervention requirements.

3.2.1. Persona 1: Knowledge-Deficient and Passive Managers

This group included 6 patients (28.6% of participants), aged 24–59 years, with disease duration ranging from 0.5 to 13 years Most had primary or secondary education and exhibited low health literacy, lacking essential knowledge about SLE self-management (e.g., infection prevention, comorbidity management, diet, emotion, exercise, perinatal care). They adopted a passive attitude toward self-management, with poor medication adherence and low confidence in symptom management. Illness uncertainty was high, as they often felt confused about disease flares and indicator fluctuations.

Patient Quote (P1): "Eating hormones can cause osteoporosis in my hands and affect my ability to make clothes. I want to know how to manage it."

Patient Quote (P4): "I still puzzled about why those indicators keep raising while I haven't felt any fatigue."

Patient Quote (P5): "I can't avoid infection. Even if I wear a mask properly, if someone sneezes, I will catch a cold. My immunity is even lower than that of a child."

Patient Quote (P11): "I don't know what I can eat and what I can't eat. For example, someone told me not to eat mushrooms, but I saw some patient's WeChat groups telling us that we can eat mushrooms. Now I still don't know if we can eat mushrooms or not."

Patient Quote (P16): "I want to know some knowledge about the fertility for men with lupus. For example, do I need to adjust the medication when I want to have a child? Will my child inherit this disease?"

Patient Quote (P21): "I am prone to anxiety, anxiety will affect my sleep, so that I have to stay up late, but I don't know how to relieve my anxiety. And I know lupus patients need contraception, but I don't know what kind of contraception is appropriate."

Core needs included simple and accessible educational materials (e.g., illustrated booklets, video tutorials), regular follow-up with personalized guidance, and step-by-step self-management guidelines to

reduce confusion.

3.2.2. Persona 2: Role-Overloaded and Conflict-Prone Managers

This group consisted of 3 patients (14.3%), aged 30–36 years, with disease duration of 7–10 years. They were primarily middle-aged individuals with multiple social roles (e.g., full-time employees, parents of young children, caregivers for elderly family members). Work and family pressures led to significant time constraints, resulting in irregular medication, missed follow-up appointments, and limited exercise. Emotional instability (anxiety, irritability) was common, and they struggled to balance the role responsibilities and disease management.

Patient Quote (P3):"I take care of both of my children by myself and there is no one to help me. There are a lot of things at home, so I only occasionally go back to the hospital for follow-up appointments."

Patient Quote (P10):"My medication schedule depends on my work. If I work in the afternoon, I may take my medication at 10 o'clock, and if I work in the morning, I may take my medication at 7 o'clock, and I rarely exercise. Every day, I go to work, get off work, go home, browse Tik Tok and go to bed."

Patient Quote (P17):"The major reason for the recurrence of the disease was the psychological pressure of marriage and work pressure. I was a little worried about whether they would mind if I couldn't give birth normally. Then the wedding was prepared for a week. It was relatively tired and cold at the end of the year. At that time, the work was also busy. During the epidemic period, I had to ask for leave and sign with the dean. Various factors led to the sudden onset of lupus encephalopathy."

Key needs included flexible self-management plans adaptable to busy schedules, stress management tools, and support from employers (e.g., reduced workload, no night shifts) and family (e.g., assistance with childcare).

3.2.3. Persona 3: Risk-Aware and Motivated Managers

This group included 4 patients (19.0%), aged 21–27 years, with disease duration of 2–9 years. They had a clear awareness of disease severity and the risks of complications, often driven by personal experiences of disease flares or observing severe outcomes of other patients. This awareness fostered strong self-management motivation, with active adherence to medication, regular follow-up, and positive coping with symptoms. However, they still faced challenges related to physical symptom burden and occasional lack of specific management skills.

Patient Quote (P8):"Recently, an actress dead because of this illness. I have come to realize the severity of this illness, so I will become more disciplined."

Patient Quote (P12):"I have seen others flare up. There was an elderly person in the same ward who seemed to have stopped taking drugs. The doctor gave her several bottles of hormone medicine. I felt scared. Although I don't have flare, these examples around me would prompt me to engage in disease

management. But I'm a bit afraid to exercise, because my body is too tired to move, and exercise makes me feel tired, I'm worried that getting any more tired could lead to disease flares."

Patient Quote (P19):"I am afraid of disease flares, so I try to manage my illness, but I just can't take medication regularly."

Patient Quote (P20):"I stopped taking medicine before and knew the consequences and seriousness of stopping medicine, so I take medicine regularly now. But sometimes I still forgot to take my medication and I don't know how to solve this problem"

Their key needs included personalized symptom management plans, real-time health monitoring tools (e.g., wearable devices), and positive reinforcement for adherence to maintain motivation.

3.2.4. Persona 4: Support-Dependent and Collaborative Managers

This group consisted of 4 patients (19.0%), aged 28–56 years, with disease duration of 0.25–12 years. Most had college education or above, exhibiting high trust in medical staff and social support systems. They actively sought professional guidance from healthcare providers, as well as emotional and practical support from family, friends and fellow patients. Adherence to treatment plans was good, and they adopted a collaborative attitude toward disease management. However, they were highly dependent on external support and needed continuous feedback to maintain engagement.

Patient Quote (P2):"My doctor told me not to sunbathe, so I dare not sunbathe anymore. Whenever there is sunlight, I will use an umbrella. In fact, my daughter may know more about this disease, I don't know much."

Patient Quote (P13):"The main reason why I was able to manage my illness well was the encouragement from my doctor."

Patient Quote (P14):"My friends always help me relax, and my husband really cared about me after I was ill, this was the biggest support for me."

Patient Quote (P18):"Every time I go for a follow-up visit, my leaders and colleagues are very supportive of me. They will approve me leave and share my work. Sometimes I feel uncomfortable, and my leaders will let me go home to rest."

Core needs included continuous professional feedback via digital platforms, peer support groups and emotional support services to address anxiety and stress.

3.2.5. Persona 5: Misconceived and Behaviorally Deviant Managers

This group included 4 patients (19.0%), aged 20–31 years, with disease duration of 0.25–7 years. They held significant misconceptions about SLE treatment and self-management, such as believing

medication was only for relieving acute symptoms (not preventing flares) or that sun protection was unnecessary if no skin symptoms were present. They often self-adjusted medication dosages based on personal feelings and engaged in risky behaviors (e.g., hair dyeing, inadequate sun protection). Family misconceptions also influenced their behaviors.

Patient Quote (P6):"I'm a man, applying sunscreen would be strange."

Patient Quote (P7):"I thought folic acid was useless, so I haven't taken it at all. I dye my hair and do nail art because I don't think it has a significant impact on my illness."

Patient Quote (P9):"Actually, my condition was quite stable at first, but my family thought that taking the medicine for too long and had side effects, so they asked me to see another doctor and switch to another medication. Later, the disease recurred."

Patient Quote (P15):"I don't feel uncomfortable in the sun, so I don't pay attention to sun protection."

Key needs included corrective health education targeting misconceptions, motivational interviewing to change risky behaviors, and family education to address false beliefs about treatment.

4. Discussion

This study identified five distinct patient personas among young and middle-aged SLE patients, highlighting the significant heterogeneity in their self-management characteristics, barriers, and needs. The findings underscore the limitations of standardized interventions and the need for precision nursing approaches tailored to specific subgroups. Each persona reflects unique combinations of health literacy, motivation, social support and role responsibilities, which align with previous research on chronic disease self-management heterogeneity [23].

In this study, for patients with low health literacy and passive attitudes, their main barrier is the unmet knowledge needs. These patients lack deep understanding of the importance of SLE, leading to poor adherence and disease flares. Studies have shown that the knowledge gaps hinder effective self-management in SLE patients [12]. Besides, when patients lack disease-related knowledge, they may struggle to understand the medication plans, resulting in passive, dependent or avoidant management behaviors. Furthermore, the high illness uncertainty could further undermine patients' self-efficacy, making them more prone to anxiety and helplessness when facing symptom fluctuations, which leads to passive self-management [24, 25]. For this patient group, intervention strategies should prioritize improving health literacy through simple, accessible educational materials (e.g., illustrated booklets, short videos) that address specific knowledge gaps (infection prevention, diet, exercise, perinatal care). Regular follow-up via phone or in-person visits can reinforce key messages and provide personalized guidance, while step-by-step self-management guidelines can reduce confusion and enhance confidence [26].

Among the interviewees, multiple social roles and role conflicts are the primary challenges for this young-aged subgroup, which is consistent with previous finding that work and family pressures hinder self-management in young and middle-aged chronic disease patients [14]. The pressure of balancing work and family leads to irregular medication and follow-up, increasing the risk of disease flares. Long-time stress could lead to emotional exhaustion ,further weakening patients' motivation to follow medical plans. Interventions should focus on flexibility, such as developing modular self-management plans that fit into fragmented time (e.g., short exercise sessions during lunch breaks). Digital tools (e.g., medication reminders, stress management apps) can help address practical barriers, while engaging employers and family members (e.g., advocating for reduced workload, arranging childcare assistance) can alleviate role burden [27].

Among the patients with risk-awareness and motivation in self-management, they are aware of disease severity and complication risks, actively comply with treatment due to fear of relapse, and could proactively management symptoms. However, physical symptom burden and occasional lack of specific skills (e.g., exercise intensity control) remain barriers. This "high motivation - low skill" may lead to adverse outcomes: excessive monitoring, frequent medical visits and causing anxiety. Therefore, interventions for these patients should build on their intrinsic motivation by providing personalized symptom management plans and real-time monitoring tools (e.g., wearable devices to track vital signs). Positive reinforcement, such as acknowledging adherence achievements, could sustain motivation, while targeted skill training (e.g., exercise guidance) could address practical gaps [28].

For the support-dependent and collaborative managers group, they exhibit strong support networks and high trust in medical staff. The strong physician-patient relationships and social support could improve self-management have been demonstrated [29]. The key need for this persona is continuous professional feedback via digital platforms (e.g., telemedicine, health apps). Unlike patients with low health literacy who need basic education, these patients require continuous feedback via digital platforms, which could reinforce adherence and reduce anxiety. Another critical need is peer support groups. Young and middle-aged SLE patients may feel isolated and loneliness because of the invisible symptoms (fatigue, brain fog) and lifestyle restrictions. Studies have shown peer support improves self-efficacy and treatment adherence in SLE [30]. Besides, the emotional needs could not be ignored either. Virtual communities can provide emotional support and knowledge sharing, while collaborative decision-making with healthcare providers can enhance engagement [31].

False beliefs about treatment and risky behaviors are the core issues of the misconceived and behaviorally deviant managers group, similar to previous finding that misconceptions about medication effectiveness and side effects reduce adherence [32]. Despite having a high level of education, they still have a deep misconceptions about SLE, which lead to high-risk behaviors such as self-adjusting doses, hair dyeing etc. This may be related their underestimation of the disease complexity or pursuit of physical attractiveness. Family misconceptions may also play a significant role in younger patients, emphasizing the need for family-centered education. Interventions should use motivational interviewing to challenge false beliefs and promote behavior change, combined with corrective health education (e.g.,

explaining the long-term benefits of medication, risks of inadequate sun protection). Involving family members in education could address external influences and improve treatment adherence [33].

This study extends the application of patient personas to SLE self-management, complementing existing research on chronic disease precision nursing. By identifying distinct subgroups and their unique needs, the findings provide a theoretical basis for developing personalized interventions that address heterogeneity. Practically, the personas can guide healthcare providers in assessing patients' self-management profiles and tailoring education, support, and resources accordingly. For example, healthcare professionals can use the persona framework to quickly identify whether a patient is a "Knowledge-Deficient and Passive Manager" in need of basic education or a "Role-Overloaded and Conflict-Prone Manager" requiring flexible plans and role support.

4.1. Study limitations

This study has several limitations. First, participants were recruited from a single tertiary hospital, which may limit the generalizability of the findings to patients from community settings or other regions. Second, the sample size (n = 21) is relatively small, and future quantitative studies with larger, more diverse samples are needed to validate the personas. Third, the study focused on patients' perspectives, and future research should include caregivers and healthcare providers to comprehensively understand self-management barriers and facilitators. Finally, the personas lack empirical evidence of intervention effectiveness, and future studies should test tailored interventions based on the personas to evaluate their impact on self-management and disease outcomes.

4.2. Implications for nursing practice

This study identified distinct self-management persons among SLE patients, revealing the heterogeneity in their self-management experiences, barriers, and needs. The findings suggest that incorporating a persona-based perspective into clinical practice may help healthcare professionals better recognize subgroup differences and provide more individualized and patient-centered self-management support. In particular, the identification of characteristic barriers and support priorities among different patient personas can assist medical team in tailoring nursing assessments, health education, follow-up strategies, and supportive interventions according to patients' specific self-management characteristics. Such a stratified approach may facilitate the early identification of patients at risk for inadequate self-management and support more efficient allocation of healthcare resources in SLE care. In addition, integrating patient personas into disease management programs may help promote more responsive communication, individualized support planning, and long-term self-management engagement among young and middle-aged patients with SLE.

5. Conclusions

Young and middle-aged SLE patients exhibit significant heterogeneity in self-management behaviors, which can be categorized into five distinct personas: Knowledge-Deficient and Passive Managers, Role-

Overloaded and Conflict-Prone Managers, Risk-Aware and Motivated Managers, Support-Dependent and Collaborative Managers, and Misconceived and Behaviorally Deviant Managers. Each persona has unique characteristics, barriers, and needs that require targeted interventions. Healthcare providers should adopt a precision nursing approach, using the persona framework to design personalized self-management strategies that address knowledge gaps, role conflicts, motivation issues, support needs, and misconceptions. This tailored approach can improve self-management effectiveness, enhance disease control, and ultimately improve the quality of life for young and middle-aged SLE patients.

Declarations

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Author contributions

JY C: writing – original draft, methodology, software, data curation, conceptualization. L Z: writing - review & editing, data curation, investigation, visualization. ZR H: data curation, investigation. LY Z: data curation, investigation. Y H: resources. EW S: resources, supervision, project administration. JL C: conceptualization, resources, supervision, writing - review & editing, project administration, funding acquisition. All authors have read and approved the final manuscript.

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Data availability

The datasets generated and analyzed during the current study are not publicly available due to preserve the privacy of the participants but are available from the corresponding author on reasonable request.

Ethical approval statement consent to participate

This study was approved by the Medical Ethical Committee of the Third Affiliated Hospital of Southern Medical University (No: 2023-ER-079) and was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. Written informed consent was obtained from all participants who were assured of confidentiality, anonymity, and right to withdraw from this study at any time.

Consent for publication

Not applicable

Competing interests

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

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Table 2

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