Research in Health Science
ISSN 2470-6205 (Print) ISSN 2470-6213 (Online)
Vol. 10, No. 3, 2025
www.scholink.org/ojs/index.php/rhs

Original Paper

Adolescents and Young Adults with Systemic Lupus Erythematosus Experience the Disease and the Needs of the Meta Integration

Lixia Peng[1], Yonghong Jiang[1], Feng Li[1], Xiaojia Chen[1] & Liling Wang[2*]

[1] Department of Nursing, University of Jinan, Guangzhou, China

[2] Baoan Central Hospital of Shenzhen, Shenzhen, China

Received: June 2, 2025 Accepted: June 28, 2025 Online Published: July 8, 2025

doi:10.22158/rhs.v10n3p33 URL: http://dx.doi.org/10.22158/rhs.v10n3p33

Abstract

Objective: To synthesize qualitative evidence on the illness experiences and needs of adolescents and young adults (AYAs) with systemic lupus erythematosus (SLE) to inform nursing interventions.

Methods: A systematic review (inception-Jan 2024) was conducted across nine databases (CINAHL, Embase, PubMed, Web of Science, Cochrane Library, VIP, Wanfang, CNKI, SinoMed). Qualitative studies exploring AYA SLE experiences were included. Studies were critically appraised using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research. Data synthesis followed the JBI meta-aggregation approach.

Results: Four qualitative studies (all JBI-rated moderate quality) met inclusion criteria. Analysis extracted 26 unequivocal findings, grouped them into 6 categories, and synthesized 3 overarching themes: Enduring Cyclical Distress: Persistent pain, fatigue, treatment burden, and emotional turmoil. Disease-Imposed Constraints: Disrupted education/employment, social isolation, and restricted life trajectories. Resilience and Support Needs: Desire for self-management knowledge, positive coping strategies (problem-focused, adaptive emotional, social), and external support for growth.

Conclusion: AYAs with SLE navigate profound physical/psychological suffering and significant life disruptions. They demonstrate potential for resilience but require proactive nursing support. Clinicians must prioritize mental health screening, provide tailored psychosocial interventions, and empower AYAs with self-management skills and accessible education to foster positive coping and improve quality of life.

Keywords

Adolescent, Young Adult, Systemic Lupus Erythematosus, Illness Experience, Qualitative Research, *Meta-Synthesis, Nursing Support*

1. Introduction

Systemic lupus erythematosus (SLE) is a chronic inflammatory disease of unknown etiology characterized by multi-organ involvement (Zhou, 2022). Compared to adult-onset SLE, pediatric SLE manifests more acutely with greater disease severity, prolonged clinical course, increased risk of major organ damage, and higher mortality rates (Bundhun et al., 2017; Gamal et al., 2021; Yang & Liang, 2024).The disease and its treatments significantly impact both physical and psychosocial development (Li et al., 2021). Adolescents with SLE face unique challenges as they navigate the critical transition from childhood to adulthood—a period when psychological maturation often lags behind physical development, rendering them particularly vulnerable to external stressors and subsequent behavioral/emotional disturbances (Lin & Li, 2005). Young adults with SLE encounter compounded difficulties during pivotal life transitions (e.g., entering higher education or the workforce). According to life course theory and role theory, chronic illnesses like SLE may disrupt socially expected trajectories in education, career development, and family formation by impairing youths' capacity to fulfill emerging adult roles and responsibilities (Johnson Mk et al., 2011). Empirical evidence confirms that adolescent SLE adversely affects school attendance, academic performance, employment prospects, and the attainment of independence (Erica F et al., 2014; Don et al., 2010). While qualitative studies examining this population have emerged globally, existing syntheses predominantly focus on adult experiences (Rodrigues L et al., 2021). Despite multinational qualitative investigations into adolescent and young adult (AYA) SLE experiences, a comprehensive meta-synthesis remains lacking. To holistically understand the lived experiences and unmet needs of AYAs with SLE, this study employs JBI meta-aggregation methodology to integrate qualitative evidence, thereby informing optimized nursing care strategies for this vulnerable group

2. Information and Methodology

2.1 Literature Inclusion and Exclusion Criteria

Inclusion Criteria: (1) Population: adolescents or young adults with SLE aged 11-<27 years old; (2) Interest of Phenomena: adolescents' or young adults' experience and needs of the disease; (3) Context: adolescents' or young adults' coexistence with the disease; (4) Study Design: qualitative research methodology or inclusion of qualitative research in a mixed study. Study Design: qualitative research methodology, or mixed research including qualitative research.

Exclusion criteria: ①non-Chinese and English literature; ②duplicate publications or incomplete data; ③studies with C grade of literature quality; studies with mixed design methodology, but the themes of qualitative studies could not be extracted.

2.2 Literature Search Strategy

CINAHL, Embase, PubMed, The Cochrane Library, Web of Science, Wipo, Wanfang Database, China

Knowledge Network, and China Biomedical Literature Service System were systematically examined and searched using a combination of subject plus free-word searches. The main search terms included the following: Adolescent*, Teen*, Youth*, juvenile; lupus erythematosus, systemic, Systemic Lupus Erythematosus, Lupus Erythematosus Disseminatus, Libman-Sacks Disease, SLE, cSLE, Renal Lupus, Lupus Erythematosus, Systemic; Expectation, need*, Attitude*, Experience*, Viewpoint*, Feeling*, perspective*, opinion*, cognition, Belief, motivation, personal satisfaction, comment, emotions; qualitative research, qualitative, interviews, focus groups, grounded theory, thematic analysis, thematic analysis. Additionally, relevant Chinese databases were searched using appropriate Chinese terms.

2.3 Literature Screening and Data Extraction

Extracts were completed independently by two researchers trained in evidence-based methodology and qualitative research, and included the author and year, country, sample size/age, phenomenon of interest, place of interview, and key findings. Once the data extraction was completed by both researchers, it was cross-checked, and if there was a difference of opinion, it was discussed and agreed upon or a third party was asked to evaluate the data.

2.4 Quality Assessment of the Literature

Literature quality assessment was conducted using the Australian JBI Centre for Evidence-Based Health Care Quality Assessment Criteria for Qualitative Research (2016 version) for methodological quality assessment of the included literature, and the quality assessment was conducted independently by two evidence-based nursing researchers, with each quality assessment criterion evaluated by "Yes" "No ", "unclear" and "not applicable" for each quality evaluation criterion. In case of disagreement, a third researcher made the decision.

2.5 Meta Integration Methodology

By using the pooled integration approach of Meta-integration, the researcher repeatedly reads, understands, analyzes, and interprets the findings of the included literature. Similar findings are combined and grouped together to form new categories. These new categories are then further summarized into integrated results, resulting in new ideas or interpretations.

3. Results

3.1 Literature Search Results

A total of 465 documents were initially collected and duplicates were removed using EndNoteX9 software, leaving 280 documents. Subsequently, the titles, abstracts, full texts, and overall quality of these documents were evaluated, and four documents were identified as relevant to this study. The process and results of the literature selection process are shown in Figure 1.

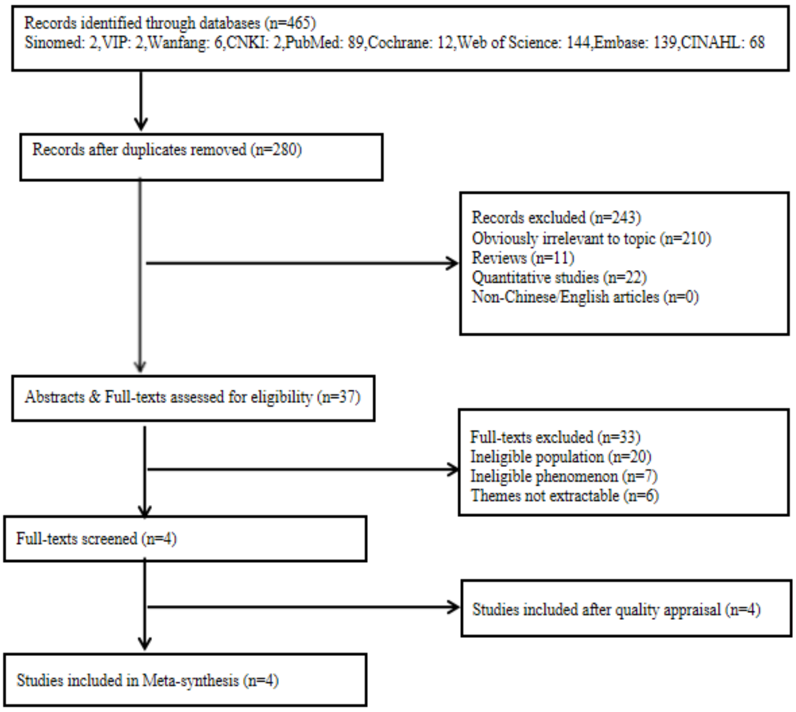

Figure 1. Study Selection Flowchar

3.2 Basic Characteristics and Quality Assessment of the Included Literature

A total of four documents were included in this study, all of which were evaluated using the Australian JBI Centre for Evidence-Based Health Care Qualitative Research Evaluation Criteria 2016 Edition The results of the methodological quality assessment showed that all four documents were graded B. None of the four documents described the status of the researcher in terms of culture, beliefs, values, or theories, and none of the four documents elaborated on the impact of the research on the study or the impact of the study on the researcher, the basic characteristics of the included literature are summarized in Table 1.

Table 1. Characteristics of Included Studies

Author(s), Year	Country	Research Method	Sample Size, Age (years)	Phenomenon of Interest	Interview Location	Main Results
Yang et al., 2023	China	Phenomenological study	11, 12-17	Physical and psychological experiences of adolescent SLE patients during the illness process	Hospital	4 themes: Negative physiological experiences; Negative psychological experiences; Disease coping strategies; Positive psychological experiences

Tunnicliffe et al., 2016	USA	Focus groups or face-to-face semi-structured interviews	26, 14-26	Experiences and perspectives of adolescents and young adults with SLE	Participants' homes, hospital, local library, or community center	5 themes: Disrupted identity; Restricted major life decisions; Multifaceted confusion and uncertainty; Resentment toward long-term treatment; Acquisition of resilience and coping skills
Harry et al., 2020	USA	Mixed-methods study (questionnaires and focus group interviews)	22, 12-24	Factors influencing self-management behaviors and QoL in cSLE patients; Barriers and facilitators to treatment adherence	Hospital	7 themes: Knowledge deficits about cSLE; Symptoms limiting daily function (mood/cognition); Barriers/facilitators to adherence; Future worries; Pain/fatigue symptoms; Self-care and management; Impact on relationships; Communication with healthcare providers
Bitencourt et al., 2021	USA	Semi-structured in-depth interviews	13, 14-26	Coping strategies and emotions during transition from pediatric to adult healthcare in SLE patients	Hospital and telephone	10 themes: Problem-focused coping; Adaptive emotion-focused coping; Social coping; Meaning making; Disengagement coping; Fear; Anger; Loss; Sense of empowerment; Excitement

3.3 Meta Integration Results

A total of 26 original findings were extracted from the four papers included, and the relevant original findings were grouped into six new categories, which were eventually consolidated into three integrative findings: Integration Finding 1: Repeated physical and psychological victimization Integration Finding 2: Resistance and Forced Confrontation due to Disease, and Integration Finding 3: Post-Traumatic Growth, Desired Support. The detailed synthesis results are presented in Figure 2.

3.3.1 Integration Outcome 1: Repeated Physical and Psychological Victimization

3.3.1.1 Category 1: Physical experience of illness

Pain is the most common symptom in people with SLE. The source of pain in adolescents with SLE can be the development of the disease itself, ("I want to be 17 like everyone else. I should be having fun... I'm doing fun things, but I can't enjoy it because my legs hurt or my head hurts... " (Harry et al., 2019)) can also be caused by pain from various tests, ("The lumbar puncture hurt a little... After the lumbar puncture, my head hurt all the time, I couldn't sleep, and it hurt so bad I would cry.") [12]) Meanwhile, fatigue is the most bothersome physical experience. ("Fatigue is the most difficult part of lupus. Lupus is a wicked disease that keeps you awake." (Harry et al., 2019))

3.3.1.2 Category 2: Negative psychological feelings associated with the disease

One of the main causes of negative psychological reactions among adolescents and young adults is the destruction of their self-image caused by the disease itself and by medication. First of all, these people experience changes in their self-image, such as redness and weight gain, which cause people around them to look at them in an unusual way. ("It's really hard to go to school. I'm on strong. Loose and now fat, so I get bullied a lot."(Tunnicliffe et al., 2016)) Changes in appearance can also bring about negative emotions, leading them to develop prejudice against themselves, which manifests itself in dissatisfaction with their external image and a reduced sense of self-efficacy. ("When the stimulant medication was reduced to about 7 tablets, my face was so fat and chubby that I couldn't cover it up with my beauty face, it was so ugly." (Y. Yang et al., 2023) Facing ridicule from others about the impact of their illness can be challenging for adolescents and young adults. However, there are also adolescents or young adults who deliberately do not want others to know about their illness. ("I don't want people to know I have it, I want to appear to be like them.... I take my medication at home, not at school. I take it, I don't want my classmates to know that I take it.... (other than my family) I only have one special friend who knows that I'm sick, but she doesn't know about it. I'm sick, but she doesn't know exactly what the disease is, the fewer people who know the better, for fear of blind rumors." (Y. Yang et al., 2023)) In addition, the disease and treatment process brings with it many unpleasant experiences, such as prolonged diagnosis, unknown etiology, and uncertain prognosis, which can create a sense of uncertainty for adolescents and young adults. ("When is the next flare? It might transfer to another organ, or if it gets worse, or if it gets better, you don't know." (Tunnicliffe et al., 2016)) The uncertainty of life often leads them to worry about future issues such as school, career, and childbearing. ("Sometimes I worry, sometimes I get sick at work, if my blood is bad my doctor comes to me. It ruins me and all I can do is cry. It's happened a couple times, but it does worry me because it's unpredictable" (Tunnicliffe et al., 2016)) at particular stages of the disease such as the onset, progression, or the transition from adolescence to adulthood, all of which can lead to mood swings such as fear, anger, and loss in these age groups. ("When I was a pre-teen I thought it was a lot easier because (my mom) did everything and I was just attending appointments... but now I have to sign papers and I have to do this and I have to do it on my own... so it's makes me feel overwhelmed." (Bitencourt N et al., 2021)).

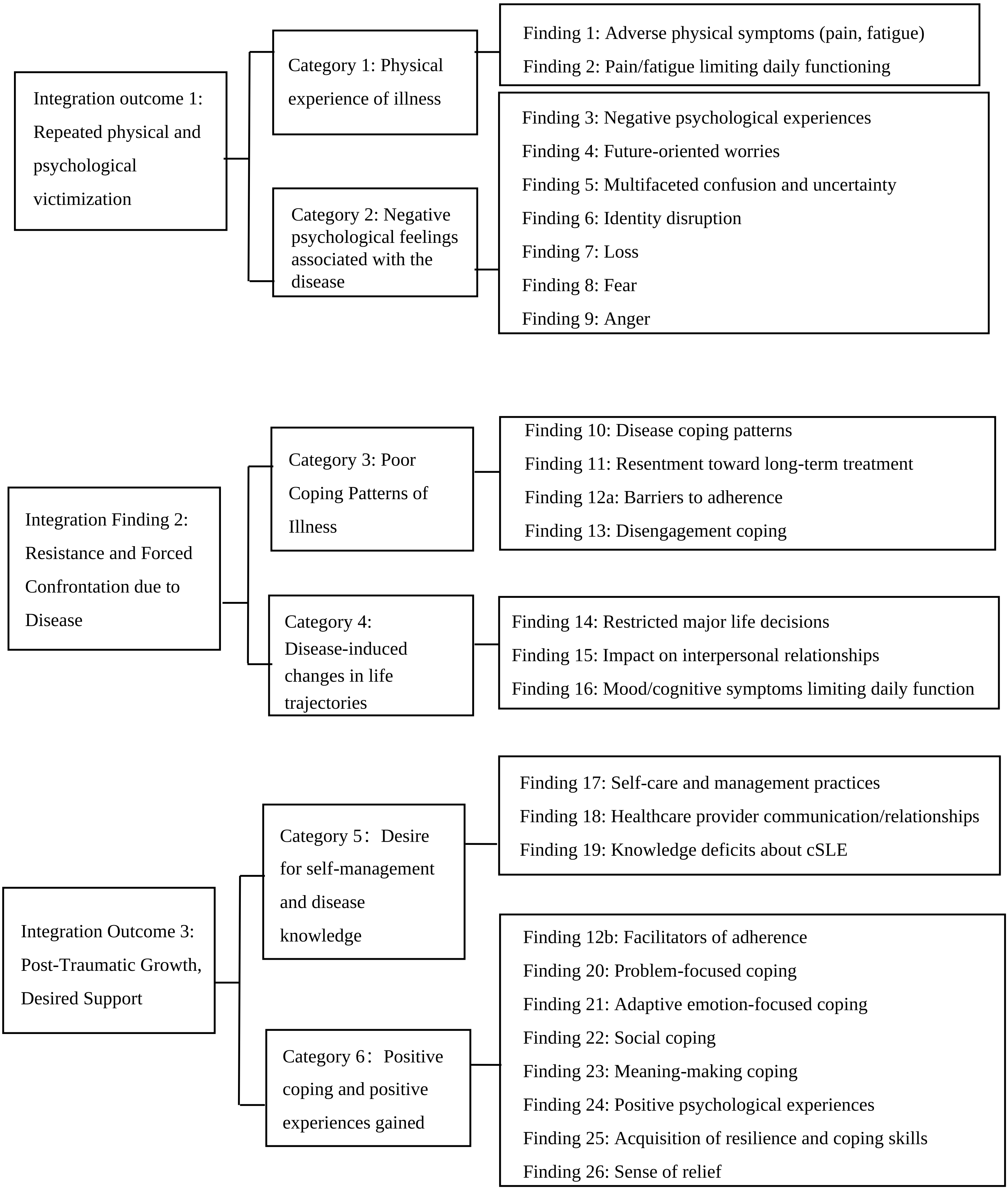

Figure 2. Process Diagram of Research Findings Integration

3.3.2 Integration Finding 2: Resistance and Forced Confrontation due to Disease

3.3.2.1 Category 3: Poor Coping Patterns of Illness

In the course of disease management, healthcare professionals will ask SLE patients to adhere to a number of requirements, such as adherence to medication and sun protection, but for newly diagnosed patients, there is often resistance ("I don't think I have any problems, so why do I need to take this medicine?" (Tunnicliffe et al., 2016)) Disease treatment is a long term process and does not show immediate results, ("All the medicines I'm taking, I don't see immediate results... What is the purpose of taking them?"(Harry et al., 2019)) Meanwhile, the treatment process is usually accompanied by adverse reactions. ("Emergency medication for me really has a lot of side effects." (Tunnicliffe et al., 2016)) In response, adolescents and young adults may feel resentment toward this long-term treatment.

3.3.2.2 Category 4: Disease-induced changes in life trajectories

For young people attending school, SLE makes them susceptible to fatigue, inability to concentrate on lessons, and interruptions in learning due to treatment, all of which can lead to a decline in academic performance. ("My goal is to get into Qingdao"). I was always taking time off work to go to the hospital, I couldn't keep up with my studies, and I felt like my goal was out of reach." (Y. Yang et al., 2023)) People with SLE need to take care of a lot of things in their lives, they need to avoid light, and some of them have limited mobility and cannot participate in strenuous sports, which prevents adolescents from participating in regular school activities, and for young adults it can also limit their career choices. ("Lupus affected me in college because I wanted to go into archaeology, and I went to a seminar and learned that archaeology has to be in the sun a lot and you have to be 100 percent healthy, so I had to change my major.") (Tunnicliffe et al., 2016) Meanwhile, most teens and young adults are reluctant to share their diagnosis with friends or significant others and are lonely on the inside, ("Lonely, even when you're with people you care about, you still feel lonely." (Harry et al., 2019))

3.3.3 Integration Outcome 3: Post-Traumatic Growth, Desired Support

3.3.3.1 Category 5: Desire for self-management and disease knowledge

Adolescents and young adults perceived a lack of knowledge about SLE, some of them chose to look up knowledge online, ("When I first found out, I really wanted to know what it was, so I looked up everything online.") (Tunnicliffe et al., 2016)) For this age group they were eager to take care of themselves, and of course they wanted knowledge that they could understand. ("Unscientific talk. (When my doctor) explained that it's cells and stuff, I said, I'm 17." (Harry et al., 2019)

3.3.3.2 Category 6: Positive coping and positive experiences gained

Adolescents and young adults also had positive psychological experiences of living with the disease, such as feeling cared for by their families, peers, and schools during the illness ("The class teacher would ask my classmates to take care of me. For example, I am prone to infections, so if there are classmates around me who have a cold, the homeroom teacher will tell them to put on a mask." (Y. Yang et al., 2023)) In living with illness, adolescents and young adults also learn to be independent, ("I've grown up, I've become stronger and more independent because my parents are from a non-English speaking country. It's hard for them to understand what it's all about, so basically since I've been sick I do everything by myself." (Bitencourt N et al., 2021)) At the same time, they had a variety of ways of coping with the illness, problem-centered coping, ("I feel like because I'm a young adult I can't rely on my mom to remember my appointments like I did when I was in pediatrics so I think I should be proactive and keep track of my own appointments." (Bitencourt N et al., 2021)) Adaptive Emotion-Centered Coping, ("Avoiding self-blame, I just need to tell myself, remind myself that what I'm going through isn't my fault, but that's what I need to do if I'm going to be here, alive, and living with my family.") [14]) then social coping, meaning making coping, etc., and in the process they also have positive emotional experiences, they feel a sense of empowerment, excitement, ("Transitioning from a child to an adult, has made me stronger... I've learned how to be calmer at I try to make sense of things and try to pick myself up because when I found out I had lupus it wasn't good... I kind of lost my character... but it also taught me how to keep my emotions in check!

Threads... It helped me get my head together... Transitions can be tough. Nothing can be whitewashed but you have to persevere. You can't give up...the whole transition is not easy but it's worth it. Once you get used to it and you realize I'm an adult, once you can go to the doctor on your own and drive yourself to the doctor, you'll feel mature and you'll feel like you've done it all. You don't feel like you're a burden to anyone, and that feels really good. "(Bitencourt N et al., 2021))

4. Discussion

4.1 Adolescents and Young Adults with SLE Suffer Repeated Physical and Psychological Injuries that Require Attention to Their Mental Health

Adolescents with SLE endure negative physical experiences with the disease and treatment, most notably pain and fatigue, which were experienced in the same way as the adult group (Cardwell et al., 2023), in line with Jones, J. T. et al.'s study (Jones et al., 2016; Knight et al., 2015). In addition, they experienced negative psychological experiences such as peer ridicule and isolation in the face of body image changes, and concerns about the future. The loss and fear of the disease process can also affect them. These negative physical and psychological experiences predispose patients to psychological disorders (Li et al., 2021), and studies (Fruzsina et al., 2022) have shown that patients with SLE have higher anxiety-depression depression indices than patients with other disorders. In addition to focusing on the disease-related aspects of the problem, the clinical aspects of psychological problems should not be ignored. For these patients, the method of narrative medicine can be used to establish contact with them, and arrowheads smoke, etc. (Z. Y. He, 2023; Wang, 2021) With narrative care into the SLE patients, narrative medicine can encourage them to externalize the disease, reconstruct, rewrite the internal heart story, and help them to face the disease positively (Cheng & Xu, 2021; Cui et al., 2021; Yan et al., 2021). At the same time, these patients should be supported by the school and society. Popularizing the knowledge of related diseases is crucial for them so that the public can understand SLE diseases and know how to protect them better. The way to popularize the disease is to use the

Internet to popularize medical science, or schools can carry out related publicity activities, such as making blackboard posters, etc. In addition, there are foreign organizations to promote SLE. In addition, therapeutic recreational camps for SLE have been organized abroad, and therapeutic recreational camps have been proposed to improve the quality of life of adolescents with chronic illnesses (Moola et al., 2014). There is evidence of short-term psychosocial benefits of camps for children with chronic illnesses (e.g., diabetes, inflammatory bowel disease, etc.), including improvements in social interaction, acceptance, self-perception, and autonomy (Andrea et al., 2011; Moola et al., 2014). Cristina Saez et al. (2022) summarize the psychosocial health benefits of adolescents and young adults who participated in SLE camps at, including the impact on cSLE disorders educational opportunities about the experience of the disease, improved adherence through peer modeling, an overall increase in self-efficacy, and a better understanding of the patient's experience by parents. No similar programs are currently operating in the country and it is hoped that they will in the future.

4.2 Adolescents and Young Adults with SLE need Positive Guidance to have Positive Experiences and Adopt Positive Coping Methods

We have found that young people and adolescents have positive emotional experiences of living with SLE (Bitencourt N et al., 2021; Y. Yang et al., 2023). They cope with the illness in a variety of ways, including confronting problems, adaptive emotions, social support, and empowerment (Bitencourt N et al., 2021). Of course, they also experience negative coping and failure to move from negative to positive coping. Therefore, in clinical practice, we need to actively assess the current state of young and adolescent patients and guide them towards positive coping. In China, studies on the coping styles of SLE patients have been conducted mainly in the adult group and parents of children (Ding & Zheng, 2021; L. J. He & Song, 2021), and there are no studies on the coping styles of adolescents and young adults with SLE in China. We hope to further develop the research in this area in order to find suitable coping styles for this group in China and summarize these styles in order to help this group to cope with SLE effectively.

5. Conclusion

The aim of this study was to compile information on the experiences and needs of adolescents and young adults with SLE in order to inform clinical practice. However, we found that most of the studies did not account for the cultural background and values of the researchers, which may have led to a risk of bias in the results. In addition, due to language limitations, we were only able to include published studies in both English and Chinese, resulting in a small number of studies, and therefore the results may not be comprehensive.

References

Andrea, B., Szabolcs, T., Gyöngyi, K., Ildikó, B., Annamária, S., & Gábor, T. (2011). Health-related quality of life changes of children and adolescents with chronic disease after participation in therapeutic recreation camping program. *Health and Quality of Life Outcomes*, *9*, 1. https://doi.org/10.1186/1477-7525-9-43

Bitencourt N, Ciosek A, Kramer J, Solow Eb & Bermas B, T. (2021). 《You Just Have to Keep Going, You Can’t Give Up》: Coping mechanisms among young adults with lupus transferring to adult care. *Lupus*, *30*(14). https://doi.org/10.1177/09612033211061057

Bundhun, P. K., Kumari, A., & Huang, F. (2017). Differences in clinical features observed between childhood-onset versus adult-onset systemic lupus erythematosus: A systematic review and meta-analysis. *Medicine*, *96*(37). https://doi.org/10.1097/MD.0000000000008086

Cardwell, F. S., Elliott, S. J., Barber, M. R., Cheema, K., George, S., Boucher, A., & Clarke, A. E. (2023). Canadian patient experiences of lupus nephritis: A qualitative analysis. *Lupus Science & Medicine*, *10*(2). https://doi.org/10.1136/lupus-2023-000982

Cheng, Y., & Xu, Y. E. (2021). The Emotional and Moral Practices of 《Presence》:Reviewing The Temperature of Nursing. *Medicine & Philosophy*, *42*(18), 73–76.

Cristina, S., Lorien, N., Tracey, W., Ue, M., Justin, K., Bonnie L, B., E. Blair, S., & Nicole, B. (2022). Therapeutic recreation camps for youth with childhood-onset systemic lupus erythematosus: Perceived psychosocial benefits. *Pediatric Rheumatology Online Journal*, *20*(1). https://doi.org/10.1186/s12969-022-00702-w

Cui, J. R., Hu, L. H., Wan, K., Xiao, H., & Xiao, H. Y. (2021). Relationship between humanistic care quality and narrative competence among clinical nurses. *Journal of Nursing Science*, *36*(09), 58–60.

Ding, Z. Y., & Zheng, L. P. (2021). Effect of nursing intervention based on story theory on coping style and self-care ability of patients with systemic lupus erythematosus. *Journal of Clinical Psychosomatic Diseases*, *27*(03), 152–156.

Don, R., Daniel, A., Melissa, S., Robert, D., Simcha, R., Rosalind, R.-G., & Sandra, N. (2010). Impact of systemic lupus erythematosus on health, family, and work: The patient perspective. *Arthritis Care & Research*, *62*(2). https://doi.org/10.1002/acr.20077

Erica F, L., Aimee O, H., Laura, T., Emily, von S., Megumi J, O., Jinoos, Y., & Edward H, Y. (2014). Educational and vocational outcomes of adults with childhood- and adult-onset systemic lupus erythematosus: Nine years of followup. *Arthritis Care & Research*, *66*(5). https://doi.org/10.1002/acr.22228

Fruzsina, K., Péter, K., Janssen Global Services LLC, G.-O., Melinda, K., Melinda, S., Chetan S, K., & György, N. (2022). High risk of depression, anxiety, and an unfavorable complex comorbidity profile is associated with SLE: A nationwide patient-level study. *Arthritis Research & Therapy*, *24*(1). https://doi.org/10.1186/s13075-022-02799-6

Gamal, S. M., Fouad, N., N, N., Badr, W., & Sobhy, N. (2021). Disease characteristics in patients with juvenile- and adult-onset systemic lupus erythematosus: A multi-center comparative study. *Archives of Rheumatology*, *37*(2). https://doi.org/10.46497/ArchRheumatol.2022.8888

Harry, O., Crosby, L. E., Smith, A. W., Favier, L., Aljaberi, N., Ting, T. V., Huggins, J. L., & Modi, A. C. (2019). Self-management and adherence in childhood-onset systemic lupus erythematosus: What are we missing? *Lupus*, *28*(5). https://doi.org/10.1177/0961203319839478

He, L. J., & Song, Z. J. (2021). Effects of positive psychological intervention based on the concept of evidence-based medicine on psychological resilience and coping style of patients with systemic lupus erythematosus. *Clinical Research and Practice*, *6*(01), 133–135. https://doi.org/10.19347/j.cnki.2096-1413.202101046

He, Z. Y. (2023). *Growing Thorn: Rheumatic Immune disease of adolescents illness experience and narrative reconstruction—A case study of Shanghai A Hospital* [Master's Thesis]. East China University of Science and Technology.

Johnson Mk, Crosnoe R, & Elder Gh. (2011). Insights on Adolescence from A Life Course Perspective. *Journal of Research on Adolescence : The Official Journal of the Society for Research on Adolescence*, *21*(1). https://doi.org/10.1111/j.1532-7795.2010.00728.x

Jones, J. T., Cunningham, N., Kashikar-Zuck, S., & Brunner, H. I. (2016). Pain, Fatigue, and Psychological Impact on Health-Related Quality of Life in Childhood-Onset Lupus. *Arthritis Care & Research*, *68*(1). https://doi.org/10.1002/acr.22650

Knight, A. M., Knight, A. M., Vickery, M. E., Fiks, A. G., & Barg, F. K. (2015). Barriers and facilitators for mental healthcare in pediatric lupus and mixed connective tissue disease: A qualitative study of youth and parent perspectives. *Pediatric Rheumatology Online Journal*, *13*. https://doi.org/10.1186/s12969-015-0049-1

Li, J. J., Shi, Y. J., & Zhou, W. (2021). Psychological status and influencing factors of children with systemic lupus rythematosus. *Journal of Shandong First Medical University & Shandong Academy of Medical Sciences*, *42*(10), 797–800.

Lin, C. D., & Li, Q. (2005). Characteristics of Physiological and Mental Development of Adolescents. *Journal of Beijing Normal University(Social Sciences)*, *01*, 48–56.

Moola, F. J., Faulkner, G. E. J., White, L., & Kirsh, J. A. (2014). The psychological and social impact of camp for children with chronic illnesses: A systematic review update. *Child: Care, Health and Development*, *40*(5). https://doi.org/10.1111/cch.12114

Rodrigues L, Sim-Sim Mmf, Sousa L, Faria-Schützer Db, & Surita Fg. (2021). Self-concept and body image of people living with lupus: A systematic review. *International Journal of Rheumatic Diseases*, *24*(11). https://doi.org/10.1111/1756-185X.14187

Tunnicliffe, D. J., Singh-Grewal, D., Chaitow, J., Mackie, F., Manolios, N., Lin, M., & O'Neill, S. (2016). Lupus Means Sacrifices: Perspectives of Adolescents and Young Adults With Systemic Lupus Erythematosus. *Arthritis Care & Research*, *68*(6). https://doi.org/10.1002/acr.22749

Wang, D. W. (2021). *Application of narrative nursing in pregnant women with systemic lupus erythematosus* [Master's Thesis]. Qingdao University.

Yan, Y. Y., Wang, L., Wang, M. Y., & Chang, K. Y. (2021). Application of Narrative Evidence-based Medicine Model in Nursing:A Theoretical Review. *Military Nursing*, *38*(07), 78–81.

Yang, X. X., & Liang, L. J. (2024). Progress in the Treatment of Systemic Lupus Erythematosus in Children. *Journal of Ningxia Medical University*, *46*(07), 735–740. https://doi.org/10.16050/j.cnki.issn1674-6309.2024.07.016

Yang, Y., Li, J., Lian, D. M., Chen, Y. X., & Li, Y. (2023). The illness experience of adolescent patients with systemic lupus erythematosus: a qualitative study. *Chinese Journal of Nursing*, *58*(01), 60–67.

Zhou, W. (2022). Diagnosis and treatment strategy of childhood-onset systemic lupus erythematosus. *Journal of Clinical Pediatrics*, *40*(10), 721–725.