Outlook Formation Process Among Individuals with Systemic Lupus Erythematosus Experiencing Concurrent Symptoms: A Grounded Theory Study

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Abstract

Background: Living with a chronic illness entails adaptation, coping and understanding own life situation. There exist gaps on how individuals with SLE, as they experience fatigue and its concurrent symptoms, make sense/process all of these as they live with the condition?

Objectives: To explore the process between fatigue, the presence of concurrent symptoms and its social-psychological aspects.

Methods: Corbin and Strauss (Straussian) grounded theory (GT) approach was used in this study. Before this study's conduct, reflexivity was observed by the authors. In this study, thirteen (N=13) (13 female aged 19-58) individuals who qualified the inclusion criteria participated in the study. Three (N=3) additional female participants diagnosed with SLE validated the findings and suggestions were carried out. Individual audio-recorded telephone and videoconferencing interviews were conducted between October-December 2021. The data analysis included open, axial, and selective coding combined with a software program for qualitative data analysis. After initial purposeful sampling, theoretical sampling and constant comparative technique were used to further enrich the data.

Results: Pain (10/13) was the most frequent symptom that occurred concurrently with fatigue as reported by participants. Here we report that based on the findings, process of outlook towards their functioning was developed among participants as evident in three major categories: Reliance (justifying the experience), Passiveness (being open and accepting), and Independence (efforts to gain control) and supported in nine sub-categories. Outlook on functioning in this study refers to the individual's appraisal, interpretation, or general attitude towards their functioning as they make sense of their condition and various forms of social interactions. Theoretical assumptions developed include: (1) individual outlook buffers the influence of social support to the outcomes, (2) the nature and source of social support influences the individual outlook, and (3) outlook on functioning is individualized and context based.

Conclusion: As reported in numerous studies that social support buffers outcomes however in this grounded theory study, the concept of outlook which refers to an individual's critical interpretation of the various forms of social interactions exists. In other words, social support does not always buffer antecedents to outcomes but also serves as an antecedent to outlook.

Impact: Further studies to prove the theoretical assumptions should be conducted and to explore the role of outlook to outcomes. Outlook should be included when assessing symptom experience.

Keywords: Chronic illness, grounded theory, systemic lupus erythematosus, qualitative, nursing, fatigue

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Introduction

Systemic lupus erythematosus (SLE) is an autoimmune disease which has no cure and with varying global incidence and prevalence. Individuals with SLE, given the nature of the disease, experienced SLE-related fatigue, and its concurrent symptoms, having issues on functioning and quality of life. As reported in various studies, one of the most common symptoms of SLE imposing limitations and challenges on individuals and affecting their quality of life is fatigue. Even individuals with mild and inactive disease manifest SLE-related fatigue (Elefante et al., 2020). While fatigue is negatively associated with all measures of functioning (Tench et al., 2000) and negatively influences the quality of life (Elhone et al., 2007), it is also associated with other symptoms such as depression (Azizoddin et al., 2019), anxiety (Du et al., 2018), hysteria (Omdal et al., 2003), sleep quality (Chiang et al., 2019), stress (Azizoddin et al., 2019) and pain (Palagini et al., 2014).

Despite this, various studies showed that social support plays an important role to coping to the disease experience of individuals with SLE. For example, healthy social relationships significantly impacted women's ability to cope with stress and self-manage this disease (Dunlop-Thomas et al., 2014). A qualitative study's findings also showed that a greater potential to remain in employment when modification of work patterns and support from colleagues and management were available (Booth et al., 2018). Given the influence of fatigue on quality of life and functioning and the positive impact of social support on coping, there exist gaps on how the individual makes process all of these as they live with the condition. While investigations describing the adaptation or coping of individuals with SLE are important, there remains the question, what is the process of achieving coping or adaptation?

This article is geared towards understanding that process, to promote holistic and individualized care and to improve the quality of life of individuals with SLE having concurrent symptoms and given the nature of their condition. With enhanced quality of life, mortality can be mitigated even without new therapies (Barber et al., 2021). Therefore, our aim is to explore the process between fatigue and the presence of concurrent symptoms given its social-psychological context.

Methods

Study Design

Corbin and Strauss's (2008) version of the grounded theory approach was used in this study. While the grounded theory is an inductive, experience-driven method and grounded in the data field, Strauss and Corbin's grounded theory method was used because it allows insights from literature review and the use of a computer software for data analysis and, has a focused research question (Streubert & Carpenter, 2011). GT was used to understand a less explored phenomenon and is geared towards the understanding of a process involving multiple concepts towards the development of an explanatory representation of the concepts.

Setting and Participants

We recruited participants from an online lupus support group in the Philippines. During the initial stage of the recruitment, we created a temporary study site where prospective participants could view study-related information and interview questions. Aside from online recruitment, an alternative recruitment mechanism for admitted individuals with SLE in a select hospital was in place to recruit additional participants; however, there were enough participants recruited online.

The inclusion criteria were as follows: 1) confirmed SLE diagnosis for at least six months using the SLICC Criteria (Petri et al., 2012) was used initially as the criteria however because other components of the SLICC criteria cannot be ascertained from an online method, participants disclosure of their clinical diagnosis became the bases for inclusion; 2) age is 18 and above; 3) presence of symptoms of fatigue along with other concurrent symptoms reported subjectively; 4) ability to answer questions; and 5) agreed to be interviewed. Adults with SLE were excluded if they had: 1) impairments with the ability to hear, speak and think; 2) if they were very sick to be able to answer the interview questions; 3) if the reason for hospitalization was related to surgery or complications; 4) if they have psychosocial concerns.

Purposeful sampling was used during the initial phase of the study. After data saturation was achieved, we shifted to theoretical sampling, which helped in enriching and clarifying the categories formulated.

The interview setting is naturalistic, which means where the participant lives, works, or is hospitalized. Interviews were done using audio-recorded videoconferencing platforms or telephone interviews available to the participants. Physical limitations and risks posed by the pandemic necessitate the choice of interview platforms. The participants set the time and date of the interview. There were thirteen participants in the study and three more who validated the findings. Although the generally accepted number of participants is 25, we relied on data saturation and the richness of data. Few published grounded theory studies used a sample of eleven (Soanes & Gibson, 2018) and fifteen (Neill et al., 2013) participants.

Data collection

Individual videoconferencing (N=12) and telephone (N=1) interviews were conducted between October 2021 and December 2021. A semi-structured interview guide translated in Filipino was developed by the principal investigator (JBT) with initially broad and open questions such as “Tell me about your experience of fatigue along with other symptoms?" (translated in English). Data saturation was reached during the interview of the 7th participant noting the recurrence. All interviews used the Filipino language. After each interview, handwritten memos were immediately done and kept in a privately owned notebook. Audio recordings were transcribed verbatim. We kept a medical teleconsultation hotline available for any untoward incidents. All participants completed the interview without any discomfort and/or severe symptoms.

Data analysis

Data collection and analysis were done simultaneously and iteratively following each interview. In the analysis, we used the three-phase process of open, axial, and selective coding (Corbin & Strauss, 2008). We used the qualitative software program (MAXQDA-Trial Version) to aid in organizing, storing, and analyzing data.

In the open coding, the transcripts were re-read line-by-line to examine what concepts or patterns were represented in the participants' accounts of their experiences using an "in vivo" coding and concept description. All coded segments were reviewed for accuracy and appropriateness.

In the axial coding, each coded segment was assigned to a color-coded folder created based on what abstract concept, construct, or pattern they may represent. There were eight grouped coded segments initially. The files were reviewed for the soundness of the groupings of the coded segments. Based on this review, nine grouped coded segments that represent the sub-categories of the study were created. As the sub-categories are built grounded in the data, we reviewed them on their overarching relationships and patterns. Based on this process, three major categories were identified.

Data saturation was reached at the 7th participant. To enrich the categories, theoretical sampling and selective coding were initiated when the data showed recurrence of the participants' accounts of their experiences. Then, interviews continued until the thirteenth participant guided by a focused question.

We followed an interpretive perspective to identify a core category from the grouped data. Two questions in doing this guided us: (1) "What is the deeper understanding that emerged from the grouped data?" and (2) "How do people construct social meaning from this situation?” The core category identified in this study was the Process of Functioning Outlook Formation.

Rigor

We ensured trustworthiness following the four evaluative criteria of Lincoln and Guba (1985), such as credibility, transferability, dependability, and confirmability. Credibility is present in this study because we suspended our preconceived beliefs and built trust with participants through informal talks before asking the interview questions. The findings of this study may also be transferable because the core category, major, and sub-categories are described sufficiently, understandably, and thickly, allowing its applications to other contexts. The dependability of the findings was achieved by validating the findings from individuals with the same characteristics as the study sample and having interview questions that can capture the phenomenon of interest. Also, three invited participants ascertained the findings and offered suggestions. Finally, the study findings are confirmable because we maintained transparent methods and procedures and kept a detailed audit trail. Tables describing the categories and sub-categories and a figure explaining the core category are available to aid in better understanding the study's findings.

Ethical considerations

This study was approved by the University of the Philippines Manila Ethics Review Board with an approval number 2020-790-01. Complete confidentiality and anonymity were maintained by removing all possible identifying information of the participants from the transcripts and the results. Participants' agreeing to participate in the interview, setting the time and platform, and continuing to answer the interview questions implied consent. Other details of their rights and scope in participating in the study were explained prior to each interview.

Results

Socio-demographic characteristics

Thirteen participants aged 19-58 participated in this grounded theory study. All participants were female (13/13) and of Filipino ethnicity (13/13). The mean age of the participants was 39.62, married (6/13), currently unemployed (7/13), and with child/children (7/13). Three additional female participants validated the findings. The most frequent symptom that occurred concurrently with fatigue was pain (10/13), followed by sleep disturbance (2/13), mood changes (2/13), feeling of being ill/sick, and loss of appetite (2/13) and sadness (1/13). Table 1 shows fatigue and its concurrent symptoms.

There were 179 coded segments related to the phenomenon of interest. The core category Process of Functioning Outlook Formation was evident in the nine sub-categories, and three major categories. The core category represents an intertwined response on how the outlook of individuals is developed as they experience various social interactions. Functioning outlook as emerged in this study refers to the individual’s critical appraisal, interpretation, or general attitude of the various social interactions. Functioning is closely connected to the experience of multiple symptoms because it brings various ranges of limitations in activities. Table 2 shows the core category, major categories, and sub-categories.

Table 1
SLE-related fatigue and its concurrent symptom/s

Participant Code	Fatigue	Pain	Sleep Disturbance	Sadness	Mood alterations	Others
1	Fatigue	Body pain; Frequent Headache				
2	Fatigue	Pain				
3	Fatigue	Pain felt on the hands and stomach			Mood changes	
4	Fatigue	Pain	Difficulty falling asleep		Mood changes	
5	Fatigue					Being ill/sick
6	Fatigue	Pain				
7	Fatigue		Difficulty falling asleep			
8	Fatigue			Sadness		
9	Fatigue	Back pain				
10	Fatigue	Back pain				
11	Fatigue	Bone pain				Appetite loss
12	Fatigue	Pain				
13	Fatigue	Joint pain				

Table 2

Core category, major categories, and sub-categories

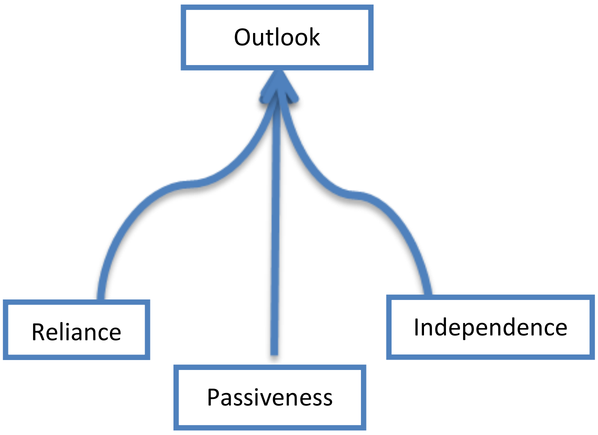
Core Category	Major Categories	Sub-categories
Process of Functioning Outlook Formation	*Reliance*	a. Rumination on past health-related behaviors b. Availability of social support
	Passiveness	a. Feeling of empathy for the primary care providers b. Navigating social isolation c. Unavoidable physical limitations and environmental barriers
	Independence	a. Symptoms masking b. Efforts to strengthen the self c. Acquiring mastery of the condition d. Refitting activities of daily living

Core category, major categories, and sub-categories

As seen in Figure 1, three intertwined components of how an outlook is developed which include: Reliance (justifying the experience), Passiveness (being open and accepting), and Independence (efforts to gain control). The outlook may influence various outcomes and it buffers various forms of social interactions.

Figure 1

Outlook Formation Process



Reliance

Reliance, which is closely connected to dependence exists in various forms where participants cling, rationalize, justify, or depend on something relative to their experience shaping later their functioning outlook. Rumination on past health-related behaviors is a sub-category where individuals cling on what could have caused their present condition, Participant 2 “I did not neglect myself; I ate on time.” Participants also put emphasis on the importance of the Availability of social support because if they are supported at work or at home, they gain self-confidence in performing their daily activities, Participant 10 for example, "Yes, my self-esteem and confidence in my work, especially when they ask me ‘What should I do?’ I think I can do something, that my opinions matter, and that I am valued. So, it gives me the will to live because you know you have a value."

Passiveness

Passiveness as a response to helplessness is an attitude of being open and accepting to social and environmental limitations imposed by concurrent symptoms and their condition. Participants became helpless and had a Feeling of empathy for the primary care providers as participants witnessed how they care for them “Participant 3 mentioned, “I pitied my parents even more because sometimes, they could not do anything and could not help me with what I felt. They can only embrace me." Living with the condition, participants had experienced Navigating with social isolation because symptoms and physical changes became a deterrent to quality social interactions and activities Participant 10, “And because of that, I became anti-social, because I would rather rest because I still have worked the next day.” With the experience of multiple concurrent symptoms, participants also had Unavoidable physical limitations and environmental barriers whether it is the work or at home, for example, “Participant 12 mentioned, "My body is very different from before. Until now, when I commute in Manila, where the stairs are high, and you need to go up and down, I get short of breath. I feel very tired. I try to catch my breath, adding to the difficulty of the mask I wear."

Independence

Independence which is closely connected to self-management refers to the active efforts to gain control over self. Symptoms masking was practiced by participants to hide their state or condition and prevent their family to worry, Participant 13 “At first, of course, I was happy because I was with them…I did not make it obvious that even though my foot hurt, I pretended that I was okay, we were okay…I didn't make it obvious.” In attempt to maintain independence, participants had made Efforts to strengthen the self, for example, Participant 8 mentioned, "I just accepted the complicated things. My condition is difficult, but it feels like okay” while Participant 3 expressed, "I feel stronger with what I feel. I become more positive because they still want to care for me even if they see how bad I feel." By living with the condition and the presence of multiple concurrent symptoms, participants were Acquiring mastery of the condition, for example Participant 9 mentioned “Before, I could not control when I experienced stress; I do not know what to do but what I do to handle the stress is I watch a movie." Some Refitting of daily activities were needed, for example Participant 6 mentioned, "I do not drink anymore. I also slept early and started an exercise routine. Before, I do not usually do exercise. I also juiced vegetables even do I am not used to it."

Discussion

The core category unraveled in this grounded theory reflects how the individual interprets various forms of social interactions, environmental barriers, and personal challenges towards their functioning. This process of outlook formation is a critical aspect of nursing care as symptom experience is subjective and individualized. The process of outlook formation with three components: Reliance (justifying the experience), Passiveness (being open and accepting), and Independence (efforts to gain control) are a result of various social interactions be it a positive experience or a negative one. Based on these findings theoretical assumptions were developed include: (1) individual outlook buffers the influence of social support to the outcomes, (2) the nature and source of social support influences the individual outlook, and (3) outlook on functioning is individualized and context based.

Various studies have reported on moderating or buffering role of social support to outcomes. For example, the negative impact of low resilience on individual mental health was buffered by social support (Li et al., 2021). In addition, as the value of the perceived social support, being the moderator variable, changes the negative life events and levels of depressive symptoms also changes (Miloseva et al., 2017). However, our study showed that as a response to various forms of social interactions including social support an outlook towards their functioning was developed among participants which impacts how they see their functioning.

Various studies have touched on some of the sub-categories uncovered in this study. Delmar et al. (2006), in their qualitative study among individuals with chronic illness have highlighted that self-control and self-responsibility are values significant to daily activities and decisions. They also described that independence and managing own self is connected to dignity and respect. Our study showed that participants, to achieve independence, had masked their symptoms to prevent their care providers to worry, strengthened themselves, gained mastery of their condition and modified their lifestyle.

Furthermore, in another study a wide range of adaptations have used by adults with chronic physical illness and disability which include among others, optimizing performance and gaining help from others (Gignac et al., 2000). In our grounded theory study, participants relied on the availability of social support and felt empathy towards them. In our study we considered them not as a form or means of adaptation but a component in how their outlook towards their functioning was formed.

One of the dimensions of the Revised Symptom Management Model (SMM) (Dodd et al., 2001) is the symptom experience which includes the aspects of individual perception, evaluation and response to a symptom and having bidirectional relationships with each other. The symptom experience influencing and interacting with the three domains of nursing (person, health and illness, and environment) are also critical in symptom management strategies and outcomes.

Our study showed that participants felt that there are unavoidable physical limitations and environmental barriers related to fatigue and experience of multiple symptoms which is closely connected to the concept of perception of symptoms (involves noticing changes in the feeling and behavior). Also, closely related to the concept of evaluation of symptoms (involves evaluating the cause, severity, and impact on their lives) in the SMM are the sub-categories (1) rumination on past health-related behaviors and (2) navigating social isolation. Lastly, sub-categories such as (1) efforts to strengthen the self, (2) acquiring mastery of the condition, (3) refitting activities of daily living, (4) feeling empathy for the primary care providers and (5) symptoms masking are sub-categories closely connected to response to a symptom (multidimensional response to a symptom). However, our study showed that the sub-categories emerged supporting a process on how an individual develops his/her outlook towards functioning as they live with the condition and experienced multiple symptoms.

Limitations of the Study

This study utilized a qualitative approach which does not aim to explain causation. The findings are also limited to individuals with SLE having fatigue and concurrent symptoms. Since all participants were female, it should also be limited to the female population having unique social roles. The use of videoconferencing and telephone interviews as means to collect data may also limit the breath of data interpretation because non-verbal cues or body language cannot be observed fully.

Conclusion

Living with a chronic condition without a cure entails adaptation, coping and understanding own situation. This grounded theory uncovered that outlook was developed from three components which include: Reliance, Passiveness, and Independence. This finding highlights the individualized and unique responses to various social support. Therefore, nurses must incorporate this finding on the timing/frequency, manner, planning, method, or measure of nursing interventions provided to individuals with chronic illness.

Implications

Our research findings shed light on the process of functioning outlook formation among individuals with SLE experiencing concurrent symptoms. Provision of nursing care and evaluation of its effectiveness should always consider the point of view of the individual. When evaluating concurrent symptoms of individuals with chronic condition such as SLE, it is also best to include the social support system, individual’s perception to their condition and environmental context. Further studies should be conducted on the role of individual outlook on patient outcomes.

Conflict of Interest

JBT and LMST have no conflict of interest to declare.

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Authors’ Contribution

JBT and LMST contributed from conception to final revision of this study.

References

Azizoddin, D. R., Gandhi, N., Weinberg, S., Sengupta, M., Nicassio, P. M., & Jolly, M. (2019). Fatigue in systemic lupus: the role of disease activity and its correlates. *Lupus*, *28*(2), 163–173. https://doi.org/10.1177/0961203318817826

Barber, M. R. W., Drenkard, C., Falasinnu, T., Hoi, A., Mak, A., Kow, N. Y., Svenungsson, E., Peterson, J., Clarke, A. E., & Ramsey-Goldman, R. (2021). Global epidemiology of systemic lupus erythematosus. *Nature Reviews Rheumatology*, *17* (9), 515–532. https://doi.org/10.1038/s41584-021-00668-1

Booth, S., Price, E., & Walker, E. (2018). Fluctuation, invisibility, fatigue – the barriers to maintaining employment with systemic lupus erythematosus: results of an online survey. *Lupus*, *27*(14), 2284–2291. https://doi.org/10.1177/0961203318808593

Chiang, Y. C., Huang, J. L., Wang, C. H., Lee, H. C., Lee, M. Y., & Hsiao, Y. C. (2019). Symptom clustering in patients with childhood-onset systemic lupus erythematosus. *Journal of Advanced Nursing*, *75*(1), 54–62. https://doi.org/10.1111/jan.13825

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research :Techniques and procedures for developing grounded theory* (Third). SAGE Publications, Inc. https://doi.org/https://www.doi.org/10.4135/9781452230153

Delmar, C., Bøje, T., Dylmer, D., Forup, L., Jakobsen, C., Møller, M., Sønder, H., & Pedersen, B. D. (2006). Independence/dependence - A contradictory relationship? Life with a chronic illness. *Scandinavian Journal of Caring Sciences*, *20*(3), 261–268. https://doi.org/10.1111/j.1471-6712.2006.00403.x

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., Lee, K., Miaskowski, C., Puntillo, K., Rankin, S., & Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, *33*(5), 668 –676. https://doi.org/10.1046/j.1365-2648.2001.01697.x

Du, X., Zhao, Q., Zhuang, Y., Chen, H., & Shen, B. (2018). Fatigue of systemic lupus erythematosus in China: Contributors and effects on the quality of life. *Patient Preference and Adherence*, *12*, 1729–1735. https://doi.org/10.2147/PPA.S170984

Dunlop-Thomas, C. M., Cooper, H., Barham, T., & Drenkard, C. M. (2014). Bridging the social support needs gap for African American women with systemic lupus erythematosus through the chronic disease self-management program. *2014 ACR/ARHP Annual Meeting*, 1–3. https://acrabstracts.org/abstract/bridging-the-social-support-needs-gap-for-african-american-women-with-systemic-lupus-erythematosus-through-the-chronic-disease-self-management-program/

Elefante, E., Tani, C., Stagnaro, C., Ferro, F., Parma, A., Carli, L., Signorini, V., Zucchi, D., Peta, U., Santoni, A., Raffaelli, L., & Mosca, M. (2020). Impact of fatigue on health-related quality of life and illness perception in a monocentric cohort of patients with systemic lupus erythematosus. *RMD Open*, *6*(e001133), 1–7. https://doi.org/10.1136/rmdopen-2019-001133

Elhone, K. M. C., Abbott, J., Shelmerdine, J., Bruce, I. an, Ahmad, Y., Gordon, C., Peers, K., Isenberg, D., Ferenkeh-koroma, A., Griffiths, B., Akil, M., Maddison, P., & Teh, L. (2007). Development and Validation of a Disease-Specific Health-Related Quality of Life Measure , the LupusQoL , for Adults With Systemic Lupus Erythematosus. *Arthritis & Rheumatism (Arthritis Care & Research)*, *57*(6), 972–979. https://doi.org/10.1002/art.22881

Gignac, M. A. M., Cott, C., & Badley, E. M. (2000). Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, *55*(6), 362–372. https://doi.org/10.1093/geronb/55.6.P362

Li, F., Luo, S., Mu, W., Li, Y., Ye, L., Zheng, X., Xu, B., Ding, Y., Ling, P., Zhou, M., & Chen, X. (2021). Effects of sources of social support and resilience on the mental health of different age groups during the COVID-19 pandemic. *BMC Psychiatry*, *21*(1), 1–14. https://doi.org/10.1186/s12888-020-03012-1

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Miloseva, L., Vukosavljevic-Gvozden, T., Richter, K., Milosev, V., & Niklewski, G. (2017). Perceived social support as a moderator between negative life events and depression in adolescence: implications for prediction and targeted prevention. *EPMA Journal*, *8*(3), 237–245. https://doi.org/10.1007/s13167-017-0095-5

Neill, S. J., Cowley, S., & Williams, C. (2013). The role of felt or enacted criticism in understanding parent's help seeking in acute childhood illness at home: A grounded theory study. *International Journal of Nursing Studies*, *50*(6), 757–767. https://doi.org/10.1016/j.ijnurstu.2011.11.007

Omdal, R., Waterloo, K., Koldingsnes, W., Husby, G., & Mellgren, S. I. (2003). Fatigue in Patients with Systemic Lupus Erythematosus : The Psychosocial Aspects. *The Journal of Rheumatology*, *30*(2), 283–287.

Palagini, L., Tani, C., Mauri, M., Carli, L., Vagnani, S., Bombardieri, S., Gemignani, A., & Mosca, M. (2014). Sleep disorders and systemic lupus erythematosus. *Lupus*, *23*(2), 115–123. https://doi.org/10.1177/0961203313518623

Petri, M., Orbai, A.-M., Alarcón, G. S., Gordon, C., Merrill, J. T., Fortin, P. R., Bruce, I. N., Isenberg, D., Wallace, D. J., Nived, O., Sturfelt, G., Bae, R. R.-G. S.-C., Hanly, J. G., Sanchez-Guerrero, J., Clarke, A., Aranow, C., Manzi, S., Urowitz, M., Gladman, D., … Magder, L. S. (2012). Derivation and Validation of Systemic Lupus International Collaborating Clinics Classification Criteria for Systemic Lupus Erythematosus. *Arthritis & Rheumatism*, *64*(8), 2677–2686. https://doi.org/doi:10.1002/art.34473.

Soanes, L., & Gibson, F. (2018). Protecting an adult identity: A grounded theory of supportive care for young adults recently diagnosed with cancer. *International Journal of Nursing Studies*, *81*(April 2017), 40–48. https://doi.org/10.1016/j.ijnurstu.2018.01.010

Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative Research in Nursing: Advancing The Humanistic Imperative* (Fifth Edit). PA: Lippincott Williams & Wilkins.

Tench, C. M., McCurdie, I., White, P. D., & D'Cruz, D. P. (2000). The prevalence and associations of fatigue in systemic lupus erythematosus. *Rheumatology*, *39*(11), 1249–1254. https://doi.org/10.1093/rheumatology/39.11.1249