

Understanding Patients' Symptoms Management Using Objective and Subjective Indicators among Patients with Systemic Lupus Erythematosus

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Abstract

Background: Descriptive statistics have been used to document the high prevalence of sleep disorders, fatigue, and pain in patients with systemic lupus erythematosus (SLE). **Objectives:** To describe day-to-day variations in sleep indicators, physical activity level, pain, and fatigue measured using objective and subjective indicators in lupus patients with sleep disorders. **Methods:** We selected three patients with sleep disorders, measured by the Pittsburgh Sleep Quality Index score (≥ 9), out of 20 participants followed up for 4 weeks. We compared the self-rated quality of life (QoL) measured using the Pittsburgh Sleep Quality Index (PSQI) with that of objectively measured sleep indicators monitored using the Nemuri scan. The detailed data collection methods have been previously published. **Results:** The sleep status generated by the Nemuri scan revealed that Case A with a flare and Case B without a flare required frequent daytime rest. The PSQI sleep duration and sleep latency were generally in agreement with the monitored data, although the PSQI failed to capture the complexity of sleep disorders, particularly the fluctuations in the quality of sleep indicators. Patient C approximately 4 hours on weekdays and 10 hours on Saturday nights. All three cases had high fatigue levels, and their moderate-to-vigorous physical activity duration was less than one-half of duration that recommended by the World Health Association. **Conclusion:** Visual display for objective monitoring of sleep quality is an excellent tool for understanding patients who require frequent resting and irregular sleep indicators. Objective monitoring of sleep quality, along with self-rated pain and

fatigue, promotes an understanding of how patients with SLE cope with severe symptoms.

Keywords

Symptoms Management, Sleep Indicator, Physical Activity, Pain, Fatigue, QoL

1. Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease, and the severity of the disease and the types of organs involved vary substantially among patients [1]. The exact etiology of SLE is unknown; however, genetic and environmental factors play a role in the development of the disease.

SLE is difficult to diagnose because of the lack of definitive diagnostic tests. This leads to misdiagnosis and delays in reaching an accurate diagnosis (even up to 6 - 7 years) [2]. Furthermore, there is no effective treatment to stop its progression after that, and the primary treatment goals are long-term patient survival, prevention of organ damage, and improvement in health-related QoL [3].

Patients with SLE experience flares (relapse) and remission; however, the incidence and duration of flares have not been well documented. Sleep disorders, fatigue, and pain are common symptoms of SLE. The prevalence of sleep disorders varies from 55% to 85% [4], and the prevalence of significant fatigue is approximately 60% [5]. These estimates were based on cross-sectional studies, and none of them reported temporal changes in these symptoms.

Analysis of the LUPUS UK forum, which provides a platform for patients to communicate openly with their peers, revealed misunderstandings or disbelief about the symptoms that patients with SLE experience [2]. Among the multiple symptoms, fatigue and sleep disorders were the least understood by family, friends, coworkers, and physicians. Patients with SLE get comments like “but you don’t look sick.” It is common for people not to believe in the severity of symptoms and their impact on daily life, and they tend to regard patients as lazy. This phenomenon is called the “invisibility” of symptoms. Quality of life scales have been developed to quantify the impact of sleep disorders and fatigue for research. However, these scales are not integrated into the clinical record system, and the problem of “invisibility” remains unresolved. In addition to these QoL scales, objective measurements of the quality of sleep and level of physical activity may promote an understanding of the impact of fatigue and sleep disorders on the daily lives of patients with SLE.

Recent studies have shown an association between sleep inconsistency (day-to-day variability) and adverse health outcomes such as mental and cardiometabolic health [6]. Previously, we followed 20 patients with SLE to investigate daily fluctuations in sleep indicators, activity level, pain, and fatigue for four weeks [7]. After examining sleep patterns of these 20 participants measured using

a sleep monitoring device, we found unusual sleep patterns and week-to-week variability in sleep indicators in three individuals with sleep disorders (total Pittsburgh Sleep Quality Index (PSQI) > 6) [8].

Here, we present a detailed analysis of objective and subjective measures of quality of life (QoL), disease-specific QoL, and non-disease-specific QoL in three participants with SLE to facilitate the understanding of sleep disturbances and fatigue levels in patients with SLE.

2. Materials and Methods

2.1. Participants

We recruited outpatients from two rheumatology centers (a university hospital and a prefectural hospital) in western Japan between September 2017 and May 2019. Primary rheumatologists screened outpatients who met the following eligibility criteria: patients 1) were adults aged ≥ 20 years registered in the national SLE registry program and met the American College of Rheumatology classification criteria for SLE, and 2) were able to self-administer the questionnaires in Japanese. The exclusion criteria were as follows: 1) significant comorbidities that would affect QoL, such as terminal-stage cancer, and 2) overlap with other autoimmune diseases, such as rheumatoid arthritis or fibromyalgia. The last author contacted the outpatients at the clinic to explain the research protocol and obtain written informed consent. We selected three cases based on the top third PSQI score (≥ 9) with poor sleep indicators based on a Nemuri scan.

2.2. Instruments

2.2.1. Quality of Sleep Monitoring Device

A body vibrometer (Nemuri SCAN, PARAMOUNT BED Co., LTD, Tokyo, Japan) was used to objectively measure various sleep indicators. The device (78 cm \times 24.5 cm, 1.5 cm high) was placed under the mattress to measure the following sleep indicators: total sleep time [min], time in bed [min], sleep latency [min], sleep efficiency [%] (total sleep time divided by total time in bed.), wake time after sleep onset [min], and frequency of leaving bed [times]. These indicators included nighttime data because the device determines the time at which the participant went to bed and the time at which they wake up, based on censure [9] [10].

2.2.2. Physical Activities

Physical activity was measured using a 3-axis accelerometer (Medi-Walk MT-KTODZ; TERUMO Co., Ltd., Tokyo, Japan). The participants were asked to wear the device continuously except when bathing or sleeping. The device measured the number of steps taken and moderate-to-vigorous physical activity (MVPA) [min].

2.2.3. Patient-Reported Outcomes (PRO): Daily Assessment of Pain and Fatigue

1) *Pain*: The visual analog scale (VAS) was used to assess self-reported pain. The participants were asked to assess and rate their pain during the day from 0 to 100 at bedtime.

2) *Fatigue*: Fatigue was measured using a Likert scale ranging from 1 (none) to

4 (strong). The participants were asked to rate their fatigue levels each day at bedtime.

3) *PSQI* [8]: The PSQI consists of seven sleep quality components: subjective sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbances, use of sleep medications, and daytime dysfunction due to poor sleep. The PSQI score ranged from 0 to 21, and poor sleep quality was defined as a total PSQI score > 5.5.

4) *The Lupus Patient-Reported Outcomes Japanese version (LupusPRO)* [11]: The LupusPRO is a disease-specific QoL scale consisting of 43 items (eight health-related QoL subcategories with 30 items and four non-health-related QoL subcategories with 13 items) related to the daily QoL of patients with SLE during the last week (the 4th week).

5) *Short Form Health Survey-12 (SF-12)* [12]: The SF-12 is a globally used, non-disease-specific QoL scale. It comprises eight domains: physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health.

2.3. Data Collections and Analysis

Detailed data collection methods have been published elsewhere [7]. A set of questionnaires was distributed to the participants, along with two monitoring devices (the Nemuri Scan and an accelerometer). Demographic data were obtained from the questionnaire, and clinical data were extracted from medical records. Rheumatologists evaluated the SLE Disease Activity Index 2000 (SLEDAI-2K). A flare was defined as an increase of ≥ 3.0 in the total SLEDAI-2K score between the two visits [13]. Sleep quality was evaluated using the PSQI and Nemuri scan, and the VAS pain and fatigue scales were rated daily for 4-week.

3. Results

3.1. Case Presentation

Table 1 displays the demographic and clinical information. All were college

Table 1. Total PSQI and subscale scores at the start of the daily monitoring and at the end of the daily monitoring.

Case	Data collection point	Global PSQI score	PSQI subscales						
			Subjective sleep quality	Sleep latency	Sleep duration	Sleep efficiency	Sleep disturbance	Use of sleep medications	Daytime dysfunction
A	Start	13	3	3	2	0	1	3	1
	End	12	3	3	2	0	1	3	0
B	Start	10	1	2	1	1	1	3	1
	End	11	1	2	2	2	1	3	0
C	Start	5	1	1	3	0	0	0	0
	End	9	1	1	3	2	1	0	1

PSQI, Pittsburgh Sleep Quality Index; Note: 0 = very good, 1 = fairly good, 2 = fairly bad, 3 = very bad; start = QoL before monitoring; end = QoL during monitoring. The global PSQI score ranged from 0 to 21. A subscale score ≥ 2 in the end of the study is printed in bold.

graduates with more than 15 years of experience with SLE. None of the patients smoked.

Table 1 displays the total and subscale PSQI scores for the three cases, and **Table 2** displays the six sleep indicators measured using the Nemuri scan, three indicators of physical activity, and pain and fatigue by week.

3.1.1. Case A

Ms. A was a married woman in her early 50 s and a homemaker with an SLE duration of 17 years. She had a flare, and her SLEDAI-2K score was 16. Due to a flare, a high dose of prednisolone equivalent to 10.0 g/day was prescribed along with hydroxychloroquine (600 mg/day) and mycophenolate mofetil (1500 mg/day). She had high VAS pain scores (>70) in the first 3 trimesters and used acetaminophen for pain management. Her fatigue levels were high, and she had sleep disturbances (PSQI score 12).

Her subjective sleep quality was 3 (very poor) (**Table 1**). Nemuri scan data displayed fragmented sleep throughout the day, indicating visually apparent sleep disturbances (**Figure 1(a)**). She generally got up at approximately 7:00 AM to perform housekeeping on weekdays, often took a nap after 9:00 AM and/or a long nap in the afternoon, and frequently rested in bed for most of the 28 days. The PSQI subscale scores that corresponded well with the Nemuri scan nighttime sleep indicators were shorter sleep duration (2: fairly bad according to the PSQI and less than 6 hours according to the Nemuri scan) (**Table 2**). The sleep efficacy for both the PSQI (0, very good) and Nemuri scan (89%) was very good. However, there was a discrepancy between the self-rated sleep latency (3, very bad) and the Nemuri scan nighttime mean sleep latency, which fluctuated between 10 and 17 min (very good to good by the PSQI rating). She tended to rest and sleep during the daytime, and 24-hour sleep time and resting times were calculated. Her 24-hour sleep time was 505 ± 123 minutes, and her resting time (being awake in bed) was 467 ± 247 min. She reported sleeping pills > 3 times/week, which corresponded to the PSQI self-medication score (3). Regarding physical activity, the mean number of steps per day was <5000 steps/day, and the mean MVPA was very short (3.9 ± 3.5 minutes).

The SF-12 and LupusPRO subscale scores at the beginning and end of the monitoring period are displayed in **Table 3** and **Table 4**. All eight SF-12 subdomains indicated extremely poor QoL at the start and end of the monitoring period. The body pain subscale score increased from 0 to 25 and the weekly mean VAS score decreased from 71 in the 3rd week to 40 in the 4th week. For summary measures of the SF-12, the physical component summary score (PCS) was 2.8, which was close to the lowest value (2.5) reported in a Japanese population-wide survey [14]. In contrast, the mental component summary (MCS) score was close to the population average (46). Regarding the disease-specific QoL scale, most LupusPRO subscale scores were low, and the summary score of the Health-Related QoL (HRQoL) score was less than half of the previous Japanese study [9].

Table 2. Weekly average data of physical activity, quality of sleep, pain, and fatigue in 3 cases with systemic lupus erythematosus.

Case		Number of steps	Over 3 Met's activity [min]	Moving distance [km]	Total sleep time [min]	Time in bed [min]	Sleep latency [min]	Sleep efficiency [%]	Waking after sleep onset [min]	Out-of-bed [times]	Pain (0-100)	Fatigue (1-4)		
A	Week of observation	1st Mean (SD)	3360 (1113)	2.6 (2.7)	2.3 (0.8)	310 (45)	333 (41)	10 (1)	93 (3)	6 (8)	0.0 (0.0)	79 (21)	3.4 (0.5)	
		2nd Mean (SD)	5101 (1822)	4.7 (3.6)	3.5 (1.5)	307 (102)	327 (109)	13 (8)	94 (2)	4 (7)	0.1 (0.3)	76 (7)	3.9 (0.3)	
		3rd Mean (SD)	5015 (1725)	3.9 (3.3)	3.3 (1.1)	368 (75)	438 (66)	17 (13)	84 (2)	52 (27)	1.6 (1.3)	71 (35)	3.6 (1.0)	
		4th Mean (SD)	5080 (1845)	4.4 (4.0)	3.3 (1.1)	366 (34)	441 (65)	14 (8)	84 (8)	55 (47)	1.9 (2.0)	40 (28)	3.4 (1.0)	
	4-week data	Mean (SD)	4639 (1811)	3.9 (3.5)	3.1 (1.2)	338 (75)	358 (99)	14 (9)	89 (7)	29 (37)	0.9 (1.5)	66 (29)	3.6 (0.8)	
		Min	1044	0.0	0.7	211	224	5	74	0	0.0	0	1.0	
		Max	8361	11.0	5.4	525	601	48	96	135	6.0	100	4.0	
		CV	0.4	0.9	0.4	0.2	0.3	0.7	0.1	1.3	1.6	0.2	0.4	
	B	Week of observation	1st Mean (SD)	9612 (1998)	14.9 (7.6)	6.0 (1.3)	353 (46)	489 (56)	24 (21)	72 (5)	96 (34)	0.9 (0.8)	60 (0)	3.3 (0.7)
			2nd Mean (SD)	7479 (3703)	8.9 (6.9)	4.7 (2.3)	302 (57)	414 (74)	25 (16)	74 (10)	70 (40)	1.0 (1.7)	59 (11)	2.1 (1.1)
3rd Mean (SD)			7907 (1463)	8.6 (2.9)	4.9 (0.9)	286 (76)	401 (119)	34 (13)	72 (4)	71 (49)	1.9 (1.6)	20 (13)	3.4 (0.5)	
4th Mean (SD)			7517 (3605)	8.6 (5.4)	4.7 (2.2)	292 (81)	380 (104)	21 (8)	77 (6)	49 (25)	0.6 (0.8)	6 (5)	3.7 (0.5)	
4-week data		Mean (SD)	8176 (2938)	10.3 (6.6)	5.1 (1.8)	310 (71)	424 (99)	27 (16)	73 (7)	73 (42)	1.2 (1.4)	36 (26)	3.1 (1.0)	
		Min	1738	0.0	1.2	146	209	8	62	1	0.0	0	1.0	
		Max	14611	27.0	9.0	421	565	73	90	170	5.0	70	4.0	
		CV	0.4	0.6	0.4	0.2	0.2	0.6	0.1	0.6	1.2	0.3	0.7	
C		Week of observation	1st Mean (SD)	6098 (1491)	9.9 (3.1)	3.8 (0.9)	309 (159)	354 (187)	29 (38)	87 (3)	8 (10)	0.1 (0.3)	10 (16)	3.3 (0.9)
			2nd Mean (SD)	8232 (2370)	11.4 (4.2)	5.1 (1.3)	284 (124)	314 (119)	12 (3)	89 (6)	8 (12)	0.1 (0.3)	0 (0)	3.6 (0.5)
	3rd Mean (SD)		6614 (1336)	8.4 (3.2)	4.1 (0.9)	277 (140)	297 (139)	12 (5)	92 (4)	2 (3)	0.0 (0.0)	0 (0)	3.0 (0.0)	

Continued

	4th Mean (SD)	7594 (1925)	10.4 (3.6)	4.7 (1.1)	264 (128)	302 (132)	20 (11)	86 (5)	14 (9)	0.0 (0.0)	0 (0)	3.1 (0.3)
	Mean (SD)	7135 (2006)	10.0 (3.7)	4.4 (1.2)	284 (140)	317 (148)	18 (21)	89 (5)	8 (10)	0.1 (0.3)	3 (9)	3.1 (0.6)
4-week data	Min	2639	2.0	1.7	151	173	6	78	0	0.0	0	1.0
	Max	13,257	20.0	7.7	649	768	122	97	35	1.0	40	4.0
	CV	0.3	0.4	0.3	0.5	0.5	1.2	0.1	1.2	3.6	3.6	0.2

CV: coefficient of variation; Vas Pain ranged from 0 (none) to 100 (strong); Fatigue ranged from 1 (none) to 4 (strong); The number in bold indicates “very bad” by the PSQI standard, and the number in blue indicates “fairly bad.”

Table 3. Descriptive statistics of SF-12 for the three cases in this study.

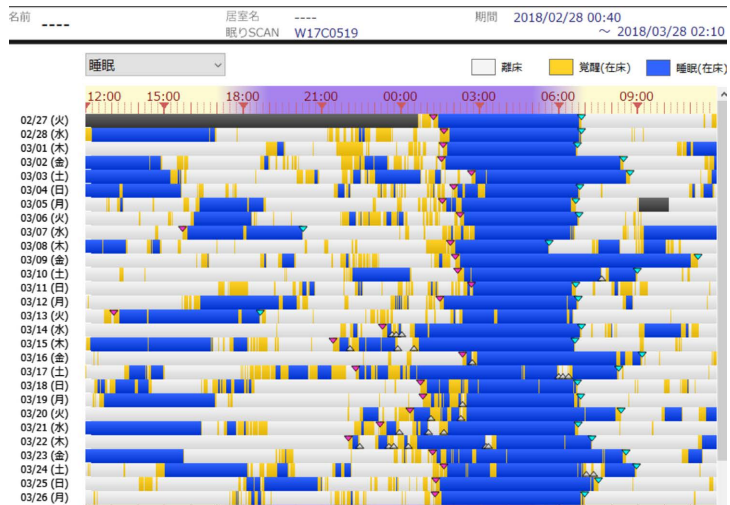
Case	Timing of data collection	SF-12 Subscales								Summary scores	
		General Health	Physical Functioning	Role Physical	Role Emotional	Body Pain	Vitality	Mental Health	Social Functioning	PCS	MCS
A	Start	25	25	0	0	0	0	13	25	3	42
	End	25	25	0	0	25	0	25	25	3	46
B	Start	25	75	50	50	25	50	75	100	28	59
	End	60	100	50	75	25	25	75	100	39	48
C	Start	60	100	100	75	100	50	75	100	55	49
	End	60	100	88	75	100	50	63	100	53	48

SF-12, short-form health survey-12; PCS, Physical Component Summary; MCS, Mental Component Summary.

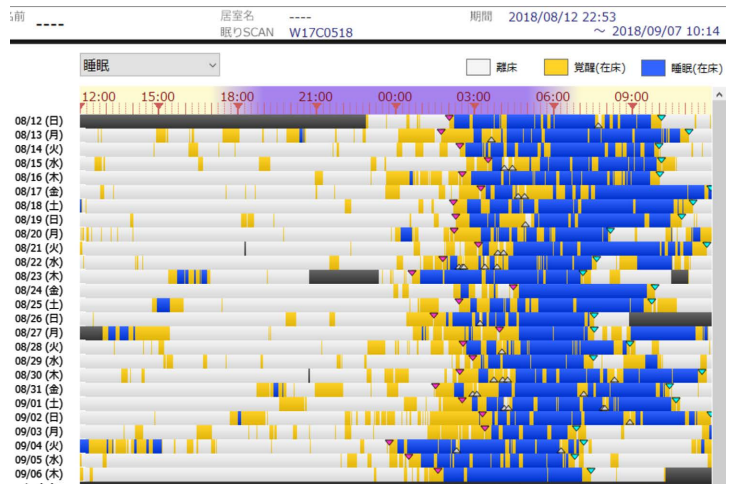
3.1.2. Case B

Ms. B was a married woman in her mid-50's with a SLE duration of 25 years. She taught at home at a cram school in the evening. The SLEDAI-2K score was low (2 points). However, her pain scores in the first two weeks of monitoring were high (approximately 70 out of 100 (Table 2)), and she used transdermal preparations for the pain. Her fatigue levels exceeded three (out of four), except in the 2nd week. She was prescribed prednisolone equivalent to 0.7 g/day and mycophenolate mofetil (1500 mg/day).

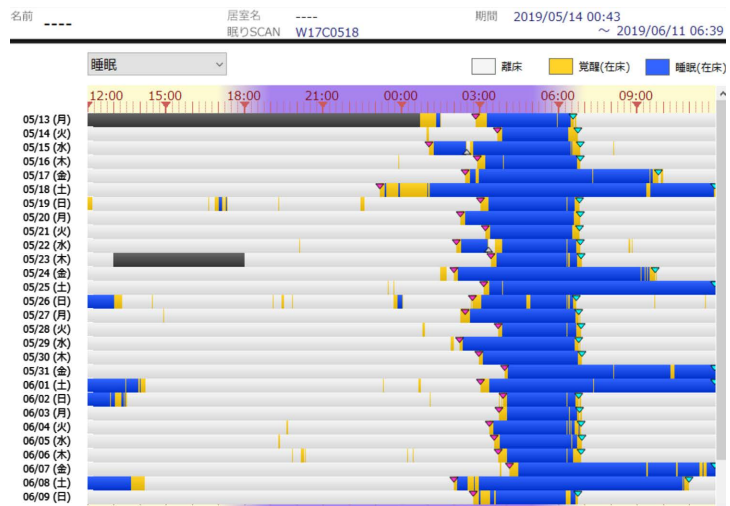
Her total PSQI score was 11, with a quality of sleep subscale score of 2 (fairly poor) (Table 1). However, her Nemuri scan showed frequent resting during the day, a long latency period, and frequent awakening at night (Figure 1(b)). Her PSQI sleep latency and sleep efficiency were in agreement with the Nemuri scan data (2 = fairly bad). Her total time in bed was 7 h/day with a relatively long sleep latency (27 min/night), resulting in low sleep efficiency (Table 2). The PSQI sleep duration score was 2. Her Nemuri scan nighttime sleep time was (310 ± 71 minutes, <5 hours/day, very bad), and 24 sleep time was 332 ± 61 minutes/day. The mean duration of waking after sleep onset exceeded 70 min. However, her PSQI sleep disturbance score was 2 (fairly good) (Figure 1(b)). She often rested in bed in the afternoon to reserve strength for evening lectures, and her



(a)



(b)



(c)

Figure 1. Sleep awake status measured by Nemuri scan for 4 weeks in three participants. Notes: gray indicates out of bed; orange indicates in bed but being awake; blue indicates being asleep.

Table 4. Descriptive statistics of LupusPRO for the three cases in this study.

Case	Timing of data collection	Lupus Symptoms	Cognition	Lupus Medications	Procreation	Physical Health	Pain Vitality	Emotional Health	Body Image	Desires-Goals	Social support	Coping	Satisfaction with care	HRQoL	non-HRQoL#
A	Start	92	13	0	100	50	40	4	5	69	25	25	100	33	62
	End	92	13	0	100	50	40	4	5	69	25	25	100	33	62
B	Start	100	100	75	NA: 0	95	100	96	100	100	0	0	100	90	62
	End	100	100	50	NA: 0	65	85	83	100	75	0	0	38	78	35
C	Start	100	88	75	88	100	95	100	95	100	25	42	50	95	60
	End	100	100	88	75	100	85	92	75	100	13	33	75	89	63

LupusPRO, lupus patient-reported outcome; HRQoL, health related quality of life; NA, not applicable; non-HRQoL, four subcategories with (#).

24-hour resting time was 247 ± 282 minutes. Her daily record of sleep medication (≥ 3 /week) corresponded with the PSQI sleep medication subscale score (3, very bad). During the 4-week monitoring period, her mean weekly total sleep time and time in bed decreased by more than 1 h, and her mean waking time after sleep onset decreased by over 40 min (Table 2). Her mean number of steps per day was 8176 steps/day (Table 2), and the mean MVPA was short (10.3 ± 6.6 minutes).

Regarding QoL measured by SF-12 at the start of the study, the general health and body pain scores were low. The mean VAS pain scores showed a decreasing trend in the last 2 weeks of monitoring, whereas the SF-body pain subscale score remained low (Table 3). Overall, the SF-12 PCS scores improved, whereas the MCS scores decreased. LupusPRO, HRQoL, and non-HRQoL scores decreased as well (Table 4).

3.1.3. Case C

Ms. C was a single woman in her mid-20s with a SLE duration of 15 years. She has a full-time clerical job. SLEDAI-2K score was low (2 points). She was prescribed prednisolone equivalent to 5.0 g/day and mycophenolate mofetil (200 mg/day). She reported little or no pain, and her mean fatigue score exceeded 3 (out of 4) at all 4 weeks (Table 2).

Her total PSQI score was 9, and her PSQI sleep quality score was 1 (fairly good) (Table 1). Her PSQI sleep latency (1 = fairly good) and sleep duration (3 = very bad) were consistent with the Nemuri scan indicators (Table 2). Her PSQI sleep efficiency was 2 (fairly bad), whereas her Nemuri scan mean sleep efficiency was 89% (very good). Her weekly mean sleep latency and waking time after sleep in minutes fluctuated over a 4-week period. Figure 1(c) shows that the patients generally went to bed after 2:00 AM, and the time to go to bed varied. On

Saturdays and/or Sundays, she was asleep for more than 10 hours. This suggests that she tried to compensate for sleep deprivation on weekdays. She did not take sleeping pills.

Her physical activity level was similar to that of Ms. B. The mean number of steps was 7135/day, and the mean MVPA duration was 10.0 min/day (Table 2).

Regarding QoL, both SF-12 PCS and MCS scores were equal to the population standards (Table 3 and Table 4). The Lupus-PRO subscale scores were higher than those reported in a previous Japanese study. Nevertheless, the social support and coping subscale scores were low, and these subscale scores were also low for the other two participants.

4. Discussion

We compared the self-rated QoL of sleep measured using the PSQI with objectively measured sleep indicators monitored using the Nemuri scan in three patients with sleep disorders. The PSQI sleep duration and sleep latency were generally in agreement with the monitored data, although the PSQI failed to capture the complexity of sleep disorders, especially frequent resting during the daytime and fluctuations in the quality of sleep indicators. Our findings suggest the use of objective measurements of sleep, in addition to relevant QoL scales, for symptom management.

The visual display of Nemuri scan sleep status data assists healthcare professionals with a better understanding of complex sleep disorders, especially in those who need frequent rest during the day and/or have irregular sleeping patterns. The global PSQI scores for Ms. A and B were approximately half of the maximum score. The PSQI does not capture fluctuations in sleep indicators. In contrast, objective sleep monitoring using the Nemuri scan can illustrate frequent resting in which the time and duration varied daily during the 4-week monitoring period.

The remaining patterns differed between Ms. A and Ms. B. Ms. A had flair and seemed to need a long nap in the morning and/or afternoon, while Ms. B, without flair, rested frequently during the daytime without falling asleep. In our previous study of 20 participants with SLE, which was derived from [7], daily sleep time for Ms. A was positively and moderately associated with the daily fatigue level recorded in the evening, whereas daily sleep time for Ms. B showed no association with the daily fatigue level. Although the cause of fatigue may differ between the two participants, the figures generated by the Nemuri scan show that both tried to perform their household duties and/or jobs by taking frequent rest.

The number of steps per day for Ms. A was 30% less than that of Japanese women aged 20 and 64 years (6685 steps/day for 20 - 64 years old in 2021) [15]. In contrast, the number of steps taken by Ms. B was 20% higher than the national average, and that taken by Ms. C was close to the national average. The number of steps is not widely used for international comparison because the steps are not comparable among individuals owing to differences in stride length. None-

theless, there were differences in the activity levels among the participants.

In contrast to the number of steps, MVPA is an important indicator of physical activity and is well documented as a preventive factor for cardiovascular diseases [16]. The mean MVPA duration for the three cases was much shorter than that recommended by the World Health Organization (WHO). In our previous study [7], Ms. A had a shorter mean MVPA duration than Ms. B. The mean duration of MVPA for Ms. A was only 14% of the WHO recommendation, whereas that for Ms. B and C was approximately half of the WHO recommendation.

Their shorter MVPA duration was probably a reflection of their high fatigue levels. Their SF12 vitality scores were low, and their daily fatigue scores were high, suggesting that their energy levels were too low to perform MVPA (e.g., brisk walking and swimming). The fatigue experienced by Ms. A and B corresponds to the description of fatigue in a qualitative study of fatigue in patients with SLE. One of the patients stated that “*You’re wore out is what it is. I guess that’s a better term. You’re just physically spent and you have to sit down, and again, that’s more predominant when you’re in flare.*” (page 100, Participant 404) [17]. Frequent daytime rest in bed by the participants indicated a frequent need to lie down to rest.

The decrease in the satisfaction with care score for Ms. B was probably noted, and reflects the different services that patients with SLE tend to use, such as dermatology and nephrology. Participants were asked to fill out a set of questionnaires while waiting for an appointment at the rheumatology outpatient department for the 1st survey and mailed the same set of questionnaires with a prestamped return envelope at the end of the monitoring. If patients receive treatment from multiple departments, their satisfaction with care subcategory needs further specification to evaluate patient satisfaction.

The LupusPRO social support scores were very low in all three cases. The Japanese validation study of LupusPRO reported a mean score of 12.5 for the social support subcategory [11]. In a US study, the mean social support score measured by LupusPRO exceeded 60 [18]. Two social support items asked if the patient received support from friends or family members. The attributes of social support proposed by Langford *et al.* [19] are emotional, instrumental, informational, and appraising. Our participants may interpret these two items as tangible support, such as financial support and running errands. Three patients had a long SLE duration, and informational support may not have been needed. A literature review suggests cultural differences in social support tendencies, and in the East Asian cultural context, people tend to value emotional suppression to maintain interpersonal harmony [20]. Qualitative studies are required to examine patients’ perceptions of social support.

The coping subcategory scores for Ms. A and B were much lower than the mean score of 42 in a Japanese study [11]. Coping is a complex concept, and there is no consensus on the structure of coping [21] in spite of the extensive research and reviews conducted on this topic [22]. Further, previous studies suggest cultural differences in the perception of coping and coping strategies be-

tween Asians and Westerners [23] [24] [25]. Two items of coping pertaining to “learning to live with SLE” and “receiving comfort/strength from my religion/spiritual beliefs” may not be culture-sensitive because the mean LupusPRO coping score is lower than that in the US study in which the mean score exceeded 60 [18]. These items may not reflect the coping status of Japanese patients with SLE, and self-perception of coping and coping strategies need to be explored in qualitative studies.

In summary, we present three cases of sleep disorders. Objective monitoring of sleep quality, along with self-rated pain and fatigue, promotes an understanding of how patients with SLE cope with severe fatigue.

5. Limitations and Strengths

Patient-reported QoL scales have been used extensively in healthcare research, and the PSQI has been used to estimate the prevalence of sleep disorders by asking about conditions during the past month. This is a useful tool for estimating the disease burden at the population level. It is not suited for describing complex sleeping problems and is used for symptom management, as sleep indicators fluctuate even within four weeks, as shown in Cases A and B.

The visual display of sleep status assists physicians in selecting sleeping pills and evaluating their effects. Physicians can easily understand high fatigue levels by looking at the Nemuri scan figures of frequent rest during the day. Daily sleep and physical activity data would help patients identify potential triggers of worsening fatigue and sleep problems. These objective data are also useful for communicating with their physicians and families about problems related to fatigue and sleep. These data also contribute to a better understanding of the problem of “invisibility”.

We did not have detailed information on the type of sleeping pill or when the participants took the pill. Information on the dosage and frequency of medication use was not collected. The participants were given feedback on all the monitored data. Nevertheless, we did not provide a detailed discussion of the monitored symptom data. Thus, we do not know the reason for Ms. C’s short sleep time on weekdays.

Our study monitored multiple indicators daily for 4 weeks, while other studies on physical activity monitoring monitored for 7 days [26] [27]. As higher variability (fluctuation) in sleep indicators is associated with adverse health outcomes [6], a minimum of 4-week monitoring is recommended in future research.

Data collection for this pilot study was labor-intensive and cumbersome, and a more automated data collection and analysis system is required for practical applications. In recent years, artificial intelligence, wearable devices, and remote monitoring have shown potential for reduced rehospitalization for patients with chronic heart failure [28]. Nurses must work with researchers in engineering and artificial intelligence to advance the measurement of objective outcomes related to fatigue. Developing fatigue indicators based on objective monitoring devices

will promote a better understanding of fatigue among patients' families and physicians. Its development is critical to evaluating the effectiveness of interventions.

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Ethics Approval

This study was approved by the Ethics Committee of Hyogo Medical University and the two rheumatology centers (IRB No. 17012). Participants were provided with verbal and written explanations to confirm their willingness to participate, and written informed consent was obtained.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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