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Development of disease-specific health-related quality of life questionnaire for Thai adolescents with systemic lupus erythematosus (SLE)

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- Introduction** : *Most instruments used for QOL evaluation are not developed specifically for SLE; hence, they present limited features when overall aspects of pediatric SLE and the responses to clinical changes are considered.*
- Objective** : *To develop a quality of life questionnaire for adolescent with lupus (QoLMEAL). A disease-specific QOL questionnaire appropriate for evaluation of Thai adolescents diagnosed with SLE.*
- Settings** : *University Hospitals in Bangkok.*
- Research design** : *Multi-center descriptive study.*
- Patients** : *Thai adolescents aged 10 - 18 years old with SLE.*
- Methods** : *The items were generated after an extensive review of the existing childhood and adolescent SLE, HRQOL literature and HRQOL evaluation as well as an expert panel discussion. The revision of items comprising QoLMEAL was performed after the pre-testing in 30 adolescents and parents. QoLMEAL has parallel adolescent and parent reports with a 5-scale for responses. Field-testing proceeds at 4 collaborating medical centers in Thailand. Assigned physicians assessed SLE activity and damage.*

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- Results** : *One hundred and twenty-eight adolescents with SLE and 123 parents participated. Mean age (SD) of the patients was 14.5 (1.9) years. A total of 66 items and 8 domains covering physical health, daily activities, family, treatment, emotional health, social, schooling, and finance were identified. QoLMEAL has acceptable content, convergent, and discriminant validity. A Cronbach's coefficient alpha of QoLMEAL is 0.94. Moderate correlation in overall domains was found between adolescent and parent reports ($r = 0.62$, $P < 0.01$). Physical health, daily activities, and treatment domains have small correlation with lupus activity or no correlation with damage indices.*
- Conclusion** : *QoLMEAL could be a SLE-specific HRQOL instrument with 66 items across 8 domains for use in SLE adolescents in Thailand.*
- Keywords** : *Quality of life, adolescent, lupus, questionnaire.*

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- บทนำ** : เครื่องมือวัดคุณภาพชีวิตส่วนมากในปัจจุบันไม่ได้ถูกจัดทำขึ้นสำหรับผู้ป่วยโรคเอสแอลอีโดยเฉพาะในกลุ่มเด็กและวัยรุ่น เครื่องมือเหล่านี้จึงไม่สามารถครอบคลุมในทุกแง่มุมของผู้ป่วยรวมทั้งอาจไม่สามารถบอกถึงการเปลี่ยนแปลงในตัวโรคได้
- วัตถุประสงค์** : เพื่อพัฒนาเครื่องมือวัดคุณภาพชีวิต Quality of Life Measure for Adolescent with Lupus ชื่อย่อว่า QoLMEAL สำหรับการประเมินรายบุคคลในวัยรุ่นไทยที่เป็นโรคเอสแอลอี
- สถานที่ที่ทำการศึกษา** : โรงพยาบาลระดับมหาวิทยาลัยในกรุงเทพมหานคร
- รูปแบบการวิจัย** : การศึกษาเชิงพรรณนารวมหลายสถาบัน
- ผู้ป่วยที่ได้ทำการศึกษา** : วัยรุ่นไทยอายุ 10 - 18 ปีที่เป็นโรคเอสแอลอี
- วิธีการศึกษา** : ชุดข้อคำถาม QoLMEAL ถูกจัดทำขึ้นภายหลังการทบทวนทฤษฎีวรรณกรรมที่เกี่ยวข้อง คุณภาพชีวิตของเด็กและวัยรุ่นรวมถึงคุณภาพชีวิตของผู้ป่วยเอสแอลอี ข้อคำถามทั้งหมดได้รับความเห็นชอบและปรับปรุงเพิ่มเติมโดยกลุ่มผู้ชำนาญการในหลาย สถาบันหลังจากนั้นได้มีการทดสอบ QoLMEAL เบื้องต้นกับผู้ป่วยวัยรุ่น 30 คน พร้อมกับผู้ปกครอง ก่อนการนำไปทดสอบจริง QoLMEAL เป็นชุดข้อคำถามซึ่งมี 5 ตัวเลือกตอบ มีทั้งฉบับวัยรุ่นและฉบับผู้ปกครองซึ่งต้องมีการตอบในคราวเดียวกัน โรงพยาบาลระดับมหาวิทยาลัย 4 แห่งในกรุงเทพมหานครเข้าร่วมในการทดสอบจริง โดยมีแพทย์ผู้ช่วยวิจัยทำการประเมินทั้ง SLE activity และ damage รวมด้วย
- ผลการศึกษา** : วัยรุ่นที่เป็นโรคเอสแอลอีจำนวน 128 รายร่วมกับผู้ปกครองอีก 123 รายได้เข้าร่วมในการทดสอบนี้ อายุโดยเฉลี่ยของผู้ป่วยทั้งหมดเท่ากับ 14.5 ปี ค่าเบี่ยงเบนมาตรฐาน 1.9 ปี QoLMEAL ประกอบด้วย 66 ข้อคำถามซึ่งถูกแบ่งออกเป็น 8 ส่วนได้แก่ ด้านสุขภาพทั่วไป ด้านกิจวัตรประจำวัน ด้านครอบครัว ด้านการดูแลรักษาโรค ด้านอารมณ์ ด้านสังคม ด้านการเรียนรู้ และด้านการเงิน ซึ่งกลุ่มข้อคำถามในแต่ละด้านมีความเที่ยงตรงในลักษณะที่คล่องจองกันของข้อคำถาม และทั้งชุดข้อคำถามมีค่าสัมประสิทธิ์ของความเชื่อมั่น Cronbach's alpha เท่ากับ 0.94 คำตอบที่ได้จาก QoLMEAL ฉบับวัยรุ่นและฉบับผู้ปกครองมีความสัมพันธ์กันในระดับปานกลาง ($r=0.62$, $P < 0.01$) ข้อคำถามด้านสุขภาพทั่วไป ด้านกิจวัตรประจำวันและด้านการดูแลรักษาโรคมีความสัมพันธ์กับ SLE activity ที่น้อยมากและไม่พบมีความสัมพันธ์กับ SLE damage

- สรุป** : QoLMEAL เป็นเครื่องมือวัดคุณภาพชีวิตที่เป็นชุดข้อคำถามแบ่งเป็น 8 ส่วน มีคำถามทั้งหมดรวม 66 ข้อ สามารถนำมาใช้ประเมินผู้ป่วยคนไทยที่เป็นโรคเอสแอลอี
- คำสำคัญ** : คุณภาพชีวิต, วัณโรค, โรคเอสแอลอี, แบบสอบถาม.

Systemic lupus erythematosus (SLE) is a fluctuating, chronic, multisystem inflammatory disease, clinical manifestations of which range from a relatively mild condition to a severe life-threatening illness. Approximately, 15 - 20% of all cases of SLE have their onset before 16 years of age.⁽¹⁾ Advances in the treatment of SLE over the five decades have dramatically improved the prognosis of children and adolescents with SLE. In the 2000s reports, the 5-year survival rate approaches 100%, and the 10-year survival rate is close to 90%.⁽²⁾ Consequently, adolescents with SLE are living longer and enter adult life with a chronic disease and morbidity as well as significant change in the quality of life (QOL).

The existing QOL measures in adolescents largely focus on the impact on physical function.⁽³⁻⁹⁾ Most of them were not developed specifically for SLE. The objective of this study is to develop a quality of life questionnaire for adolescent with lupus (QoLMEAL), a disease-specific quality of life instrument, for evaluation of individual Thai adolescent patients aged 10 - 18 years old with SLE.

Materials and Methods

Subjects

Thai adolescents 10 - 18 years of age diagnosed with SLE according to the American College of Rheumatology revised criteria (1997) for the classification of SLE, followed for at least 3 months, and able to participate in the study as determined by a pediatric nephrologist, and their parents (or legal guardians) were recruited from 4 medical centers in Bangkok. Children were excluded if they were unable to complete the questionnaires or had a significant co-morbid condition exclusive of SLE that was likely to impact the QOL.

Development of QoLMEAL

The QoLMEAL conceptualizes QOL as the adolescents' and parents' perceptions of the impact of SLE on different aspects of adolescents' life. The content of QoLMEAL was derived from: 1) review of the existing childhood SLE and HRQOL literature; and, 2) review of other HRQOL measures. Also, the initial list of QOL items in Thai is derived from pediatric nephrologists, pediatricians and nurses, cognizant of the QOL issues and experienced in managing SLE in adolescents. The content validity index (CVI), using ratings of item relevance by the content experts, was computed. The item which has CVI value less than 0.5 was revised or excluded.

The QoLMEAL features self-administered parallel adolescent self-reports and parent proxy-reports with responses in the form of a 5-point Likert response. The mean raw domain score is transformed to scores ranging from 0 (best HRQOL) to 100 (worst HRQOL). Thirty eligible patients and their parents were asked to criticize/make comments on the questionnaire and to suggest activities in their lives that had been affected by their illness that had been omitted in the questionnaire. The QoLMEAL had 8 hypothesized domains comprising of physical health (10 items), daily activity (10 items), family (4 items), treatment (13 items), emotional health (9 items), social (10 items), schooling (7 items), and finance (3 items). All questions refer the respondent to their previous month.

Data collection

Appropriate institutional review board approval was obtained from all centers. Potential subjects were identified at each center through clinic

visits or during inpatient admissions. Adolescents and parents completed corresponding versions of the QoLMEAL. Adolescents completed the questionnaires independent of their parents. The examining physicians completed the European Consensus Lupus Activity Measurement (ECLAM) and Systemic Lupus International Collaborating Clinics/ American College of Rheumatology Damage Index (SDI) for each subject after the completion of the questionnaires. The ECLAM comprises 15 weighted clinical and serological items, and scores of disease activity from 0 to 10. The SDI consists of 41 items in 12 organ systems/domains and scores of disease damage from 0 to 49. Additional data collected included the patient's date of birth, age, sex, body mass index, disease onset, current immunosuppressants and education level.

Statistical analysis

Psychometric testing of the QoLMEAL consisted of determining the construct validity and internal reliability of the measure. Construct validity

evaluates the robustness of the structure and determines the domains of the QoLMEAL. Principal component analysis with oblique rotation was conducted. The generation of factors was confirmatory. The analysis was used as a hypothesis-generating procedure to enable the most appropriate QoLMEAL structure from psychometric, psychosocial, and clinical perspectives. Internal reliability measured the extent to which items within a domain were conceptually related and were assessed using Cronbach's alpha coefficients. Internal reliability was perceived as acceptable for factors/domains with a Cronbach's alpha coefficient >0.7 . SPSS software, version 15 was used to conduct the statistical analysis. The reduced number of items was finally composed into QoLMEAL.

Results

After an extensive review of the existing childhood SLE and HRQOL literature and HRQOL measures, as well as panel discussion with the experts and experienced personals, 66 questions were

Table 1. Demographic Characteristics of 128 patients.

Characteristic	Mean (SD) or number (%)
Age (years)	14.5 (1.9)
Age of diagnosis (years)	10.9 (2.4)
Duration of SLE (years)	3.5 (2.3)
Gender: Female	98 (76.6%)
Male	30 (23.4%)
Educational status:	
Being in school	118 (94.4%)
School absence < 1 year	2 (1.6%)
School absence ≥ 1 year	5 (4.0%)

derived. Three were rephrased after pretesting in 30 patients and their parents. 128 patients and 123 parents were recruited. The patients were 98 girls and 30 boys with a mean age of 14.5 years (range 10.0 - 18.6 years). Table 1 shows the patients' demographic characteristics. The mean age at diagnosis was 10.9 years (range 4.4 - 14.7 years) and mean duration of the disease was 3.5 years (range 0.3 - 11.4 years). Most patients (94.4%) remained to continue their studies in the school.

Based on ECLAM and SDI scores, 48.5% of patients had no disease flare and 59.8% had no organ damage, respectively. The mean ECLAM score was 1.1 (range 0 - 7), and mean SDI score was 0.4 (range 0 - 2). Mean body mass index was 22.5 kg/m² (range 10.1 - 41.5). Eighteen patients (14.2%) had a history of hospitalization within one month prior to the entry of study. Sixty-three patients (49.2%) received

only steroid and 63 patients (49.2%) received steroid plus another immunosuppressant such as cyclophosphamide, azathioprine, or mycophenolate.

Table 2 shows the proportion of patients whose responses reached the maximum and minimum scores in each domain of QoLMEAL. The ceiling or floor effect possibly occurs when patients perceive that their condition has improved or deteriorated, respectively, beyond what a QOL questionnaire can scale. In this case, the floor values consistently represent well perceived QOL and ceiling values poor QOL. There was no ceiling effect and floor effects existed in some cases. These effects were minimal in the self- and proxy-report total scale score (0.9 and 3.6, respectively) and maximal in the self-report finance and proxy-report daily activity domain score (49.2 and 46.7, respectively).

Table 2. The QoLMEAL summary data, floor and ceiling effects, and missing responses: adolescent report.

Domains (no. of items in domain)	Total scores, mean (SD, range)	Floor effects (% 0 score)	Ceiling effects (%100 score)	Missing responses
All domains (66)	15.3 (10.2, 0 - 56.8)	0.9	0	21
Physical health (10)	15.5 (13.6, 0 - 65)	11.8	0	1
Daily activity (10)	7.5 (8.8, 0 - 47.5)	24.0	0	3
Family (4)	20.9 (19.2, 0 - 75)	24.4	0	1
Treatment (13)	15.9 (15.4, 0 - 84.6)	12.2	0	5
Emotional health (9)	21.5 (18.3, 0 - 83.3)	7.8	0	0
Social (10)	12.4 (13.8, 0 - 82.5)	22.9	0	10
Schooling (7)	21.8 (14.9, 0 - 89.3)	3.2	0	2
Finances (3)	14.9 (18.9, 0 - 75)	49.2	0	0

Floor / ceiling effects, the percentage scores at the extremes of the scaling range; missing responses, the percentage unable to score domain.

Table 3 summarizes the convergent and discriminant validity, and scaling success. The convergent validity is the degree to which an item moderately to strongly correlates with (converges on) its hypothesized domain. The discriminant validity is supported if an item has a significantly higher correlation with their own domain than with other domains.

Table 4 displays the value of Cronbach's alpha for the adolescent report and parent report scales. As for the overall adolescent report scale, Cronbach's alpha was 0.94. The item reduction did not make any changes in the internal consistency. The values of Cronbach's alpha for the proxy-report scales were close to the values in the self-report scales.

Table 3. Item scaling tests – convergent and discriminant validity for the QoLMEAL: adolescent report.

Domains	Convergent validity (range of correlations)	Discriminant validity(range of correlations)	Scaling success
Physical health	0.39 - 0.74	0.10 - 0.51	70/70
Daily activity	0.15 - 0.80	(-0.02) - 0.51	69/70
Family	0.56 - 0.85	0.09 - 0.58	28/28
Treatment	0.39 - 0.65	0.03 - 0.56	91/91
Emotional health	0.50 - 0.74	0.14 - 0.55	63/63
Social	0.41 - 0.74	0.11 - 0.49	69/70
Schooling	0.50 - 0.65	0.15 - 0.55	49/49
Finances	0.71 - 0.91	0.10 - 0.43	21/21

Table 4. Internal consistency reliability for the QoLMEAL

Domains	Cronbach's α	
	Adolescent report	Parent report
All domains	0.94	0.95
Physical health	0.84	0.88
Daily activity	0.74	0.85
Family	0.68	0.73
Treatment	0.87	0.83
Emotional health	0.86	0.86
Social	0.85	0.86
Schooling	0.75	0.85
Finances	0.79	0.81

Table 5. Correlation of the domains and disease activity (ECLAM index) and damage (SDI).

	ECLAM		SDI	
	Correlation coefficient	P	Correlation coefficient	P
All domains	0.21	0.055	0.06	0.508
Physical health	0.22	0.027	0.07	0.469
Daily activity	0.20	0.048	0.14	0.115
Family	0.01	0.898	-0.03	0.753
Treatment	0.23	0.026	0.02	0.865
Emotional health	0.01	0.955	-0.004	0.966
Social	0.03	0.802	0.03	0.711
Schooling	0.09	0.379	0.12	0.169
Finances	0.07	0.475	0.14	0.126

ECLAM, European consensus lupus activity measurement; SDI, Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index

Discussion

We show that the instrument is valid for teenager with SLE age 10 - 18 years old because it possesses construct validity, content validity, and internal consistency. Values of ceiling or floor effect above 20% are considered high.⁽¹⁰⁾ Almost half of our patients selected the minimum score of zero in finance domain, so the differences might not be detected between the groups with different severity by these three questions in finance domain. While there were the floor effects in other domains, this did not invalidate the questionnaire as the items contribute to the content validity. However, most of our patients were recruited from the outpatient clinic, so they had either milder or controlled disease confirmed by the results of ECLAM scoring assessment. Therefore, more studies on other patient populations are needed.

In this study, the questionnaires with incomplete data were removed from the analysis of

involved domain as well as total scale. Sixteen point four percent of the adolescent reports and 23.6% of parent reports were incomplete. We speculated that the parents might be uncertain regarding their children's SLE activities or whether SLE was under good control with their current treatment. The children might barely be asked for any help from their parents probably due to some concern about potential SLE flare.

With regard to the item-scaling analysis, the items comprising each domain mostly correlated with each other (convergent validity) and not correlated too highly with other domains (discriminant validity). However, some items in daily activity domain adolescent-report showed only small correlations not only with other domains but also with its own domain. Poor correlations suggest that they might be scaling different things from their domain. Interestingly, these items connote the very basic daily activities without

any physical exertion. Although SLE is associated with pain, bone aches, weakness, and stiffness in these children⁽¹¹⁾, our patients whose disease mostly was mild or under control might barely experience difficulty in doing these activities.

To test the internal consistency, Cronbach's coefficient is used for our study. It is a scale based on the correlations between different items on the same domain. Coefficients above 0.7 are generally regarded as acceptable for psychometric scales.⁽¹²⁾ The high value of Cronbach's α (0.94) for the entire scale indicates that the QoLMEAL has good internal consistency. With the items in each domain, Cronbach's α ranges from 0.68 to 0.87 which is comparable to the values for other validated instruments such as SMILEY (α for domain, 0.7 – 0.8).⁽¹³⁾

The level of parent-child agreement varies and is dependent on the measurement method, domains studied, and children's/parents' physical and mental health status.⁽¹⁴⁻¹⁶⁾ The observed moderate correlation between the adolescent and parent reports in our study further supports the need for parallel child and parent reports to obtain both perspectives.^(17, 18)

Our instrument only correlates weakly with the SLE activity indices and is consistent with the previous reports in adults and children (Table 5). The generic module does not correlate with SLEDAI.⁽¹⁹⁾ Only mild correlations were found between the limitation domain scores of the child SMILEY report and the SLEDAI, PGA, or SDI.⁽¹³⁾ On the other hand, other investigators have found that Child Health Questionnaire correlates with SLEDAI and SDI⁽²⁰⁾ and the SF-36 correlates with SLEDAI.⁽²¹⁾ This suggests that lupus activity and damage do not consistently perturb the QOL.

One possible explanation is that local factors and personality have more a direct effect on the subjective perception of QOL than life circumstances or disease.⁽²²⁾

We have documented the steps we have undertaken to construct a SLE-specific QOL instrument, and we show that it possesses construct validity, content validity, and internal consistency. Thus, the validity of our instrument has been established. Full validation is therefore awaiting. The work that remains to be done includes resolving its role in clinical trials and routine practice and confirming its applicability in different populations. Test-retest reliability should be assessed in the near future. Our instrument may ultimately prove itself a useful adjunct to clinical practice and research, providing valuable insight to the impact of SLE on the overall QOL of the adolescents.

Conclusion

QoLMEAL could be an instrument for measuring the quality of life of Thai adolescents with SLE. However, several limitations should be considered when interpreting our findings. Subjects were drawn from convenience sample pools. The study population was fairly homogeneous, comprised mostly of outpatient subjects. Qualitative studies were not performed due to the time limitation of the patients and parents attending the outpatient clinics and a lack of the experiences in focus group discussion or deep interviews of the investigators. Concurrent validity was not evaluated due to unavailable validated quality of life evaluation of Thai children or adolescents. The criteria used to categorize the subjects for the known-group validity evaluation may not have been sufficient

to allow for the scales to detect differences between groups. Grouping the subjects by a different criterion, such as a relevant clinical measure, may approve the findings for its known-group validity

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แบบสอบถามคุณภาพชีวิตวัยรุ่นโรคเอสแอลอี (บางส่วนของฉบับเต็ม)

ในช่วง 1 เดือนที่ผ่านมา คุณมีปัญหาเหล่านี้เกิดขึ้นมากน้อยเพียงใด

ด้านสุขภาพทั่วไป (โรคเอสแอลอีทำให้....)	ไม่เคย	เกือบ ไม่เคย	บางครั้ง	บ่อยๆ	เกือบ ตลอดเวลา
เจ็บหรือ คัน หรือ แสบที่บริเวณผิวหนัง	0	1	2	3	4
เจ็บเบื่ออาหาร	0	1	2	3	4
เจ็บปวดท้องหรือแน่นท้องมากจนไม่อยากขยับตัว	0	1	2	3	4
เจ็บปวดตามข้อหรือตามกล้ามเนื้อมากจนไม่อยากขยับตัว	0	1	2	3	4
เจ็บปวดหัว หรือ เวียนหัวจนต้องกินยาหรือพักผ่อน	0	1	2	3	4
กิจวัตรประจำวัน (โรคเอสแอลอีทำให้....)	ไม่เคย	เกือบ ไม่เคย	บางครั้ง	บ่อยๆ	เกือบ ตลอดเวลา
11. การเดินบนพื้นราบภายในบ้านเป็นเรื่องลำบากสำหรับฉัน	0	1	2	3	4
การเดินขึ้นบันไดเป็นเรื่องลำบากสำหรับฉัน	0	1	2	3	4
การวิ่งเป็นเรื่องลำบากสำหรับฉัน	0	1	2	3	4
การติดกระดุมเสื้อเป็นเรื่องลำบากสำหรับฉัน	0	1	2	3	4
การใช้ช้อนตักอาหารเข้าปากเป็นเรื่องลำบากสำหรับฉัน	0	1	2	3	4
ครอบครัว (โรคเอสแอลอีทำให้ฉันรู้สึกว่า....)	ไม่เคย	เกือบ ไม่เคย	บางครั้ง	บ่อยๆ	เกือบ ตลอดเวลา
พ่อ แม่ หรือผู้เลี้ยงดูฉันมีภาระที่เพิ่มขึ้น	0	1	2	3	4
พ่อ แม่ หรือผู้เลี้ยงดูฉันกลัวใจ	0	1	2	3	4
ด้านการดูแลรักษาโรคเอสแอลอี (ฉันรู้สึกว่า....)	ไม่เคย	เกือบ ไม่เคย	บางครั้ง	บ่อยๆ	เกือบ ตลอดเวลา
การรักษาหรือยาที่ฉันได้รับไม่ได้ช่วยรักษาโรคของฉัน	0	1	2	3	4
การรักษาหรือยาที่ฉันได้รับทำให้ฉันรู้สึกแย่ลง	0	1	2	3	4
โรคของฉันเป็นโรคที่รักษายาก	0	1	2	3	4
ฉันกลัวที่จะถูกเจาะเลือดหรือถูกฉีดยา	0	1	2	3	4
ฉันกลัวที่จะต้องไปหาหมอ	0	1	2	3	4