



Libyan Journal of Public Health Practices (LJPHP)



Journal homepage:
<https://journals.uob.edu.ly/LJPHP/index>

Pattern And Determinants of Health-Related Quality of Life Among Systemic Lupus Erythematosus Patients In Libyan Healthcare Settings

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ARTICLE INFO

Article history:

Received 24/5/2014

Revised 1/6/2024

Accepted 22/6/2024

Keywords:

Determinants
Quality of life
HRQoL
SLE
Libya

ABSTRACT

Systemic lupus erythematosus (SLE) is a long-term autoimmune disease affecting multiple systems in the body and is known to cause considerable morbidity and mortality. This study's objective was to evaluate several Health-related Quality of life (HRQoL) dimensions among SLE patients getting treatment in Libyan medical care facilities. Additionally, it examined how certain clinical and socio-demographic variables affect every HRQoL domain. A cross-sectional study was conducted at the Rheumatology Department of the Tripoli University Hospital-Libya during October 2022 and targeted patients with confirmed diagnosis of SLE. Data was collected using a self-reported questionnaire that included the RAND 36-Item Health Survey 1.0 version of the SF-36. The data was analyzed using the SPSS. A total of 50 respondents filled in the questionnaires. The mean age of the participants was 44.79 years (SD=12.31) and 80.0% of them were females. The least impacted HRQoL domains were Physical (mean=72.52, SD=28.04) and Social functioning (mean=66.25, SD=32.26). While the most affected domain was Role limitation due to emotional problems (mean=35.33, SD=41.18). Energy/ Fatigue (p=0.021) and Emotional well-being (p=0.011) scores were significantly higher in males. Physical functioning mean score was significantly higher in unmarried patients (p=0.037). The mean of Role limitation due to emotional problems score (p=0.038) and the Energy/ Fatigue scores were significantly lower in patients with comorbidities (p=0.019). The least impacted HRQoL domains were Physical and Social functioning. While the most affected domain was Role limitation due to emotional problems. The main factors associated with lower HRQoL scores were, female sex, marriage, low monthly income, and presence of comorbidities.

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1. Introduction

SLE is a chronic multisystemic autoimmune disease that associated with significant morbidity, mortality and poor HRQoL⁽¹⁾, which are more pronounced in developing countries⁽²⁾. HRQoL is a multi-domain concept that assesses patients' overall perception of the impact of the disease and its treatment on their physical, psychological, and socio-economic functions, that are not always fully captured by descriptions of the disease's physiological consequences only^(3,4). In recent years, patient-reported HRQoL has gained more attention in SLE management and is recommended to be evaluated in routine clinical practice. This provides SLE patients the opportunity to be involved in their treatment and to enhance their communication with the multidisciplinary team involved in their care⁽⁴⁻⁶⁾.

It is well known that HRQoL is significantly impaired by the SLE, particularly due to the SLE-associated musculoskeletal and mucocutaneous manifestations. In addition to arthritis, and internal organs involvement, particularly, the heart, lungs, blood vessels, liver, kidneys and nervous system⁽⁶⁻⁸⁾. However, evidence is limited and inconsistent about the predictive factors of poor HRQoL in SLE patients. In Libya, evidence is lacking about the impact of SLE on patients' HRQoL and about the main clinical and socio-demographic factors influencing the different domains of HRQoL. Therefore, the objective of this study was to evaluate several HRQoL dimensions among SLE patients getting treatment in Libyan medical care facilities. Additionally, it examined how certain clinical and sociodemographic variables affect every HRQoL domain.

2. Methodology

This cross-sectional study was done in October 2022 at the Rheumatology Department of University of Tripoli Hospital in Libya. This hospital was chosen as the research location because it has one of Libya's major Rheumatology departments, which provides comprehensive care for SLE patients. The inclusion criteria for participants were, patients

with a confirmed diagnosis of SLE, aged 18 years and older, of both sexes and who are able to give an informed consent. Recently diagnosed patients, with a duration of less than 6 months, pregnant and advanced stage SLE patients, and those who are unable to give an informed consent were all excluded.

Data was collected using a self-reported questionnaire. The first part of the questionnaire covered selected socio-demographic and clinical data. The second part was the Arabic version of the RAND 36-Item Health Survey 1.0 version of the SF-36. The RAND 36 scale assess the HRQoL, it is multidimensional, as it comprises of eight subscales that measure eight quality of life domains including; Physical functioning, Role limitation due to physical health, Role limitation due to emotional problems, Energy/Fatigue, Emotional well-being, Social functioning, Pain and General health. Scoring guidelines provided by Hays and colleagues and recommended by the RAND Corporation for this version were followed⁽⁹⁾. Responses on each item were firstly recoded into percentages, so that the highest possible score was 100, and lowest possible score was 0. The higher the score, the more the favorable the outcome. Then, the recoded responses on the items of each subscale were averaged to compute the score of the quality-of-life domain measured by that subscale. To provide a comprehensive evaluation of the important dimensions of HRQoL, each HRQoL domain was treated separately, and no HRQoL overall score or summary scores were created. Despite the prevalent use of the physical domain summary score (PCS), and mental domain summary score (MCS) in previous research, they were not employed here, firstly because the general population parameters needed to standardize the subscales scores for the Libyan population were not available, which preclude the standard PCS and MCS scoring algorithm. Furthermore, there has been a controversy around the methods used for their derivation, and concerns about their performance and accuracy⁽¹⁰⁻¹³⁾, as well as concerns about the validity of the standard scoring algorithm⁽¹³⁾ which could lead to misleading interpretation.

Likewise, although several studies employed a total HRQoL score, the scoring guidelines of the scale does not refer to a standard method to generate such a single measure, and studies that reported an overall score have either not specified their method or presented inconsistent methods⁽¹⁴⁾. Data was analyzed using the SPSS, version 26. Cronbach’s alpha coefficient was used to assess the internal consistency reliability of each of the RAND 36 subscales. Frequency and percentages were used to present qualitative data. Despite the small sample size, all quantitative data were approximately normally distributed, therefore, mean and standard deviation were used to summarize these data. Pearson's correlation, Independent t test, ANOVA test and Welch's ANOVA test were used in the bivariate analysis. For post hoc multiple comparison, Tukey's honestly significant difference (HSD) post hoc test was used when equal variance assumptions were met, while Tamhane post hoc test was used when data does not meet the assumption of homogeneity of variance. Both p value of less than 0.05, and 95% confidence intervals were considered in the interpretation of the significance of the reported differences. Effect size indices were calculated for the significant

findings to quantify the magnitude and the practical significance of the reported differences. Cohen's d effect size (*d*) was used for independent t test, Cohen's f effect size (*f*) was used for ANOVA; using partial Eta-squared (η_p^2), and the adjusted Omega-squared effect size (ω^2) was used for Welch's ANOVA. Interpretation of the results was in accordance with the following rules: Effect size *d* < 0.2 is very small, 0.2 to < 0.5 is small, 0.5 to < 0.8 is medium, and ≥ 0.8 is large; Effect size *f* 0.10 is small, 0.25 is medium, and 0.40 is large. (Cohen 1988); and ω^2 < 0.01 very small, 0.01 to < 0.06 small, 0.06 to < 0.14- medium, ≥ 0.14 large.

3. Results

A total of 50 respondents filled in the questionnaires. The age of the participating patients ranged from 20 to 74 years, with a mean age of 44.79 years (SD= 12.31). Females represented 80.0% of the cases. More than half of the participants were unmarried (64.0%) and unemployed (58.0%), with those who reported a low income ($\leq 1,000$ LD) constituted 76.0% of the sample. Out of the 50 participants, 21 (42.0%) live outside Tripoli (Table 1).

Table 1: Socio-demographic profile of the SLE patients (n=50)

Variable	f	(%)	Range
Age (years) [†]	44.79	± 12.31	20-74
Sex			
Males	10	(20.0)	
Female	40	(80.0)	
Nationality (n=46)			
Libyan	45	(97.8)	
Non-Libyan	1	(2.2)	
Marital status			
Unmarried	32	(64.0)	
Married	18	(36.0)	
Number of family members [†]	6.49	±2.65	2-14
Education level			
Preparatory school or less	14	(28.0)	
High school level or equivalent	21	(42.0)	
University level or equivalent	15	(30.0)	
Employment status			
Unemployed	29	(58.0)	
Employed	21	(42.0)	
Income(in LD)			
≤ 1000	38	(76.0)	
>1000- 1500	8	(16.0)	
>1500	4	(8.0)	
Residency			

Tripoli	29 (58.0)
Outside Tripoli	21 (42.0)
Adequate adherent	37 (74.0)

† (mean ±SD)

The mean age at which SLE was diagnosis was 34.32 years old (SD= 12.24), and 71.4% were diagnosed within a year of the beginning of symptoms, however, 12.2% were diagnosed after more than 5 years of having the symptoms. The mean duration of SLE was 11.85 years

(SD= 8.42), with 73.5% of the participants had the disease for at least 6 years. Self-reported adequate adherence to SLE medications was 88.0%, and that for keeping up with follow-up appointments was 74% (Table 2).

Table 2: Clinical profile of the SLE patients (n=50)

Variable	f (%)	Range
Presence of other chronic disease than SLE		
No	20 (40.0)	
Yes	30 (60.0)	
Age at Onset †	32.40 ±11.92	3-64
Age at diagnosis †	34.32 ±12.24	3-65
Onset to diagnosis (n=49) †	1.91 ±3.26	
≤ 1 Year	35 (71.4)	
2 to 4 years	8 (16.3)	
≥ 5 years	6 (12.2)	
Disease duration (onset to current age) (n=49)†	11.85 ±8.42	1-42
> 1 year	4 (8.2)	
2-5 years	9 (18.4)	
≥ 6 years	36 (73.5)	
Adherence to follow-up appointments		
Non adequate adherence	13 (26.0)	
Adequate adherent	37 (74.0)	
Adherence to medications		
Non adequate adherence	6 (12.0)	
Adequate adherent	44 (88.0)	

† (mean ±SD)

Table 3 displays the reliability of each of the eight HRQoL subscales and summarizes the reported scores. All of the RAND 36 subscales had adequate internal consistency reliability as indicated by Cronbach’s alpha values larger than 0.7 ^(15, 16), except for the Energy/Fatigue and General health subscales, where alpha values were low, though acceptable being larger than 0.5 ⁽¹⁷⁾. Both of these subscales had average inter-item correlation values that fall in the optimal range of (0.2-0.4) ⁽¹⁸⁾.

The least impacted HRQoL domains in this sample of SLE patients were Physical (mean=72.52, SD=28.04) and Social functioning (mean=66.25, SD=32.26), while the most affected domain was Role limitation due to emotional problems (mean=35.33, SD=41.18). Table 4 shows the relationship between selected

socio-demographic characteristics of SLE patients (age, sex, marital status and income) and their HRQoL. Among all HRQoL domains, Energy/Fatigue showed a nearly statistically significant negative and weak correlation with age. Of the eight HRQoL domains, Energy/Fatigue and Emotional well-being domains were significantly higher in males than in females. The mean Energy/ Fatigue score in males (mean=67.50, SD=17.83) was higher than that in females (mean=51.87, SD=18.59), and the mean difference was statistically significant (p=0.021), with a large effect size, which

Table 3: Health-related Quality of life in SLE patients (n=50)

HRQoL domains	Items	Mean	±SD	Observed Range	Cronbach's alpha (α)
Physical functioning	10	72.52	±28.04	0-100	0.909
Role limitation due to physical health	4	53.00	±41.23	0-100	0.840
Role limitation due to emotional problems	3	35.33	±41.18	0-100	0.813
Energy/ Fatigue	4	55.00	±19.32	20-100	0.623
Emotional well-being	5	61.44	±18.93	28-100	0.716
Social functioning	2	66.25	±32.26	0-100	0.845
Pain	2	65.10	±27.67	0-100	0.742
General health	5	52.60	±19.90	20-95	0.548

that the difference is meaningful ($d=0.857$). Likewise, the Emotional well-being score was greater in males (mean=74.80, SD=13.20) than in females (mean=58.10, SD=18.78), and the mean difference was statistically significant ($p=0.011$). The effect size was also large ($d=1.028$), which reflects the practical significance of the reported difference. The Physical functioning domain mean score was statistically significantly higher in unmarried patients (mean=79.37, SD=22.92) than in married (mean=60.34, SD=32.60); ($p=0.037$), and the effect size of the difference was medium ($d=0.675$).

There were significant variations in two HRQoL domains: Physical functioning and Energy/Fatigue among the three income groups, as indicated by Welch's ANOVA test ($p=0.030$). Tamhane post hoc test results revealed that, the group who reported an income of 1000 LD or less has a significantly lower Physical functioning score (mean=68.32, SD=30.10) compared to the group whose income was between 1000 to 1500 LD (mean=89.37, SD=10.50), ($p=0.005$), with a large Omega-squared effect size ($\omega^2=0.152$). A significant difference in mean Energy/ Fatigue score between the three income groups was indicated by ANOVA test ($p=0.031$). Tukey better in patients who have no comorbidities (mean=78.75, SD=28.41) than in those who have comorbidities (mean=57.91, SD=32.41); ($p=0.024$), with a medium effect size ($d=0.683$). The Pain domain mean score was also significantly better in SLE patients who reported

HSD post hoc test results revealed that the group who reported an income of 1000 LD and less has a significantly lower Energy/ Fatigue score (mean=51.05, SD=18.85) compared to the group whose income was 1000 to 1500 LD (mean=68.75, SD=14.57), ($p=0.043$), with a large Cohen's f effect size ($f=0.138$).

Table 5 displayed the reported relationship between selected clinical variables (disease duration, comorbidity, adherence to medications and to follow-up) and HRQoL among SLE patients. No statistically significant difference in any of the HRQoL scores was found between patients with different disease duration length. Having other chronic comorbidities along with SLE found to adversely impact several HRQoL dimensions. The mean Role limitation due to emotional problems score was significantly lower in SLE patients who reported having other chronic diseases (mean=25.55, SD=38.83) than in those who have no other morbidities (mean=50.00, SD=41.18), and the mean difference was statistically significant ($p=0.038$), with a medium magnitude ($d=0.610$). Likewise, the Energy/ Fatigue score was significantly lower in those who have other morbidities (mean=49.83, SD=19.54) than that in patients who have no comorbidities (mean=62.75, SD=16.58); ($p=0.019$), and the effect size of the difference was medium ($d=0.712$). Social functioning was significantly no comorbidity (mean=77.25, SD=28.83) than the other group (mean=57.00, SD=24.07); ($p=0.010$), and effect size of the mean score difference was medium ($d=0.762$). General health mean score was significantly lower in patients who have comorbidity (mean=47.33,

SD=20.45) compared to that in those who have no other morbidities (mean=60.50, SD=16.53); ($p=0.020$), and the size of the effect of this difference was again medium ($d=0.707$). Poor medication adherence found to adversely impact the Role limitation due to emotional problems, as its mean score was significantly lower in patients who reported inadequate adherence (mean=0.00, SD=0.00) than in those who reported adequate adherence (mean=40.15, SD=41.65) ($p=0.000$), with a very large effect size ($d=1.363$). However, no significant mean differences in any of the eight HRQoL domains was found between patients who keep up with their follow-up appointments and those who were not on regular follow-up.

The corresponding 95% confidence intervals of the mean differences in all of the above reported significant findings did not embrace the value of no difference, however, the intervals were broad, which should be considered in the interpretation of the findings.

4. Discussion:

In the present study, the most affected domain of HRQoL among SLE patients was the Role limitation due to emotional problems and the least impacted domains were Physical and Social functioning. The last was in contrast with the results of other studies, which reported a lower Physical functioning^(19, 20) and a poor Social functioning^(20, 21).

The reported Role limitation due to emotional problems in this study was significant. This could be attributed to other coincident latent factors than the SLE. The Energy/Fatigue domain showed a nearly statistically significant negative and weak correlation with age. Age does not show a relationship with any of the HRQoL domains, which is contrary to several previous studies^(20, 22- 25). However, the low statistical power of the sample may have reduced the chance to detect significant relationships between age and the eight domains.

Of the eight HRQoL domains, Energy/ Fatigue and Emotional well-being domains were significantly higher in males than in females in agreement with other published studies^(20, 26, 27). This may be explained by that, most of females

are housewives, who usually perform the living daily activities alongside with housing activities with the continuous effect of SLE during performing these activities.

Unsurprisingly, the Physical functioning domain mean score was statistically significantly higher in unmarried than in married patients, and the effect size of the difference was medium. Moreover, significant differences in Physical functioning and Energy/ Fatigue domains, were found across the three income groups.

In the present study, no statistically significant difference in any of the HRQoL scores was found between patients with different disease duration length. This was in agreement with some studies^(20, 23, 28), and in contradiction with others^(24, 29). Having other comorbidities along with SLE in the current study found to adversely impact several HRQoL dimensions, this was compatible with another study⁽²⁴⁾. The mean scores of Role limitation due to emotional problems, Energy/ Fatigue and General health domains were significantly lower in SLE patients who reported having comorbidities than in those who have no other comorbidities. Likewise, Social functioning and Pain domains mean scores were significantly better in patients who have no comorbidities than in those who have comorbidities. Poor medication adherence was found to adversely impact the Role limitation due to emotional problems. However, the cross sectional design of this study cannot establish a cause-effect relationship. No significant mean differences in any of the eight HRQoL domains was found between patients who keep up with their follow-up appointments and those who was not on regular follow-up.

Table 4: Relationship between HRQoL domains and selected socio-demographic characteristics (n=50)

Factors	RAND 36 Subscales															
	PF		RF		RE		VT		MH		SF		BP		GH	
	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD
Age	-0.195 ^a		-0.113 ^a		0.174 ^a		-0.279 ^a		0.005 ^a		0.056 ^a		-0.265 ^a		-0.173 ^a	
P value	0.179		0.441		0.232		0.052		0.972		0.702		0.066		0.234	
Sex																
Males	80.50	±30.50	52.50	±36.22	40.00	±40.97	67.50	±17.83	74.80	±13.20	71.25	±33.87	70.75	±34.66	56.50	±23.69
Female	70.53	±27.44	53.12	±42.81	34.16	±41.67	51.87	±18.59	58.10	±18.78	65.00	±32.17	63.68	±25.97	51.62	±19.06
P value	0.320		0.966		0.693		0.021*		0.011*		0.589		0.476		0.558	
Effect size	—		—		—		0.857 [†]		1.028 [†]		—		—		—	
Marital status																
Unmarried	79.37	±22.92	53.90	±40.71	29.16	±36.66	56.25	±21.44	60.00	±19.16	69.14	±33.44	69.29	±26.92	55.46	±19.56
Married	60.34	±32.60	51.38	±43.27	46.29	±47.33	52.7	±15.1	64.00	±18.76	61.1	±30.2	57.63	±28.17	47.50	±20.01
P value	0.037*		0.838		0.195		0.547		0.479		0.404		0.155		0.177	
Effect size	0.675 [†]		—		—		—		—		—		—		—	
Income (LD)																
≤ 1000	68.32	±30.10	48.68	±41.48	28.07	±39.91	51.05	±18.85	58.52	±19.38	64.47	±33.45	62.56	±28.47	49.34	±20.07
>1000-1500	89.37	±10.50	65.62	±37.64	58.33	±34.50	68.75	±14.57	68.00	±14.34	68.7	±29.8	71.87	±23.25	63.75	±14.07
>1500	78.75	±19.31	68.75	±47.32	58.33	±50.00	65.00	±19.57	76.00	±15.31	78.1	±29.5	75.62	±29.88	61.25	±21.74
P value	0.030* ^b		0.425		0.083		0.031 ^c *		0.120 ^b		0.711 ^b		0.512 ^b		0.116 ^b	
Effect size	0.152 [‡]		—		—		0.138 [§]		—		—		—		—	

* P<0.05, ^a Pearson's correlation (r), ^b based on Welch's ANOVA, ^c based on One-Way ANOVA, [†] Cohen's *d* effect size, [‡] Omega-squared (ω^2), [§] Cohen's *f* effect size, PF=Physical functioning , RF=Role limitation due to physical health, RE=Role limitation due to emotional problems, VT=Energy/ Fatigue, MH=Emotional well-being, SF=Social functioning, BP=Pain and GH=General health.

Table 5: Relationship between HRQoL domains and selected clinical factors(n=50)

Factors	RAND 36 Subscales															
	PF		RF		RE		VT		MH		SF		BP		GH	
	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD	Mean	±SD
Disease duration																
> 1 year	82.50	±18.92	62.50	±47.87	41.66	±31.91	55.00	±17.79	64.00	±21.41	68.75	±21.65	75.62	±28.75	58.75	±22.86
2-5 years	68.88	±29.23	44.44	±46.39	29.62	±42.30	56.11	±21.03	58.22	±17.90	72.22	±35.23	68.61	±29.42	54.44	±14.24
≥ 6 years	73.64	±28.18	54.86	±40.45	36.11	±43.18	55.27	±19.56	62.44	±19.39	65.97	±32.26	63.33	±27.95	52.36	±20.68
P value	0.719 ^a		0.728 ^a		0.877 ^a		0.993 ^a		0.819 ^a		0.870 ^a		0.662 ^a		0.815 ^c	
Co-morbidity																
No	77.75	±26.38	65.00	±39.23	50.00	±41.1	62.75	±16.58	65.60	±19.86	78.75	±28.41	77.2	±28.8	60.50	±16.53
Yes	69.04	±29.00	45.0	±41.2	25.55	±38.8	49.83	±19.54	58.66	±18.08	57.91	±32.41	57.0	±24.0	47.33	±20.45
P value	0.287		.093		0.038*		0.019*		0.208		0.024*		0.010*		0.020*	
Effect size	—		—		0.610 [†]		0.712 [†]		—		0.683 [†]		0.762 [†]		0.707 [†]	
Medications																
Adherence																
Inadequate	54.16	±32.15	29.16	±45.87	0.00	±0.00	42.50	±17.81	48.66	±17.60	47.91	±28.95	50.00	±25.69	42.50	±18.64
Adequate	75.02	±26.87	56.25	±40.03	40.15	±41.65	56.70	±19.07	63.18	±18.61	68.75	±32.18	67.15	±27.56	53.97	±19.87
P value	0.087		0.133		0.000*		0.091		0.078		0.140		0.156		0.188	
Effect size	—		—		1.363 [†]		—		—		—		—		—	
Follow-up																
Inadequate	69.23	±26.68	44.23	±41.02	25.64	±33.75	48.46	±17.48	58.15	±16.38	64.42	±32.21	63.46	±29.44	47.69	±21.17
Adequate	73.68	±28.77	56.08	±41.41	38.73	±43.39	57.29	±19.63	62.59	±19.82	66.89	±32.70	65.67	±27.42	54.32	±19.44
P value	0.627		0.378		0.276		0.158		0.473		0.815		0.807		0.306	

* P<0.05 , ^a based on One-Way ANOVA, [†] Cohen's *d* effect size, PF=Physical functioning , RF=Role limitation due to physical health, RE=Role limitation due to emotional problems, VT=Energy/ Fatigue, MH=Emotional well-being, SF=Social functioning, BP=Pain and GH=General health.

The study had some limitations that should be considered in the interpretation of its findings, and in further research. Self-reporting of some variables is liable to response bias, like over reporting of medication adherence. The small sample size lowers the statistical power, this might have led to failure in detecting other significant relationships between the HRQoL domains and the studied characteristics. Also, the reported confidence intervals of all significant mean score differences in HRQoL domains in this study were broad, and this can be associated with some uncertainty of the estimates, and should be considered in the interpretation of the findings. However, broad confidence interval is expected with small sample sizes. The study strength of this study was that, the reported effect sizes with all statistically significant findings ranged from medium to large, which supports their practical significance. Besides communicating the practical importance of the significant findings, the presentation of the effect size indices in this study make it easier to compare its findings with other similar studies that report the same effect sizes indexes.

5. Conclusions

Among this sample of SLE patients in Libyan healthcare settings, the least impacted HRQoL domains were physical and Social functioning. While the most affected domain was the Role limitation due to emotional problems. The main factors associated with lower HRQoL domains scores were, female sex, marriage, low monthly income, and presence of comorbidities.

This study recommends a conduction of another research with a larger sample size to identify the predictive sociodemographic and clinical factors of poor HRQoL among SLE patients. Furthermore, a provision of psychological and social support to SLE patients may reduce their Role limitation due to emotional problems and can also provide a safe atmosphere for patients to share their apprehension and experiences.

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