

ORIGINAL ARTICLE

## Evaluation of Knowledge, Disease Severity and Quality of Life of Patients with Psoriasis

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### Abstract

#### Background

Psoriasis vulgaris is a chronic immune-mediated inflammatory multi-system disease characterised by keratinocyte hyperproliferation. Data regarding patients' disease severity, knowledge and quality of life (QOL) is important to optimize treatment strategies for psoriasis. This study aims to evaluate and investigate the relationship between disease severity, knowledge and QOL of patients with psoriasis.

#### Methods

A cross-sectional multicentre study utilizing a socio-demographic data collection form, Psoriasis Knowledge Assessment Questionnaire (PKAQ), Dermatology Life Quality Index (DLQI) and Psoriasis Area and Severity Index (PASI) was conducted. Correlations between PKAQ, DLQI and PASI were analysed using Spearman's test.

#### Results

A total of 114 subjects participated in this study. Majority of them had mild psoriasis (n=73, 64%) based on PASI. The mean score of PKAQ was fourteen out of a total possible score of twenty-five, whereas the DLQI had a non-parametric distribution with a median (interquartile range) of 7 (10). Most subjects (32.5%) stated that psoriasis had a 'moderate effect' on their QOL, while only 3.5% said that it had an 'extremely large effect' on their QOL. There was a statistically significant correlation between PASI and DLQI ( $r_s = 0.264$ ,  $p = 0.004$ ), with higher PASI scores corresponding to higher DLQI scores. No statistically significant correlation was found between DLQI and PKAQ ( $r_s = -0.048$ ,  $p = 0.612$ ), and between PASI and PKAQ ( $r_s = 0.058$ ,  $p = 0.542$ ).

#### Conclusion

Impairment of QOL was positively associated with severity of psoriasis. However, there was no significant relationship between knowledge and quality of life, as well as between knowledge and psoriasis severity.

**Key words:** *Psoriasis, DLQI, PASI, quality of life, patient knowledge, Malaysia*

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#### Introduction

Psoriasis vulgaris is a chronic immune-mediated inflammatory multi-system disease characterised by keratinocyte hyperproliferation and uncontrolled epidermal differentiation. Psoriasis is characterised by bilateral,

symmetrical beefy-red plaques with thick, adherent silvery scales, often affecting nails and joints.<sup>1</sup> The global prevalence of psoriasis is about 2 to 3%,<sup>2</sup> and men have a slightly higher incidence compared to women, with a ratio of 1.3 to 1.<sup>3</sup>

The symptoms of psoriasis are highly variable within the population, with skin pain and redness being the primary reported symptoms.<sup>4</sup> Other symptoms include desquamation (68%), pruritus (41%), dry skin (40%) and erythema (30%). Although psoriasis is neither contagious nor curable, the symptoms can be well-controlled with a range of treatment modalities such as topical and systemic medication, as well as phototherapy.<sup>5</sup>

In addition to the unpleasant pain and itchy sensation, psoriasis can also negatively affect one's physical, physiological, psychological and social wellbeing. With regards to the physical and physiological wellbeing, psoriasis is associated with an increased prevalence of other chronic conditions such as obesity, hypertension, dyslipidemia and diabetes mellitus.<sup>3,6</sup> In addition to that, the psychological and social wellbeing of patients with psoriasis are often compromised, with cases of depression and anxiety frequently reported among them.<sup>7</sup> To mitigate these issues, more information is required regarding disease severity, disease knowledge and quality of life (QOL). With better information, suitable interventions can be planned to minimise the negative impacts of psoriasis on patients.

Previous studies identified a few predictors of poor QOL including young age, single status, active employment, sport activity, extensive psoriatic lesions, psoriatic arthropathy and nail dystrophy.<sup>8,9</sup> Despite many of the determinants being unavoidable, educational intervention was found to be effective in improving QOL. Azmi et al.<sup>10</sup> demonstrated a significant improvement in QOL based on the Dermatology Life Quality Index (DLQI) scores [8.64(5.66) vs 5.60(5.35), 95% CI 2.23-3.86] after 2 months of a flipchart education counselling intervention, suggesting

that knowledge of psoriasis may be associated with QOL and/or disease severity.

While QOL among psoriasis patients and the factors associated with it has been widely investigated, few studies described the knowledge level of patients regarding the disease, as well as evaluated the association between knowledge level with patient's QOL and disease severity, especially among the Malaysian population. Hence, the objective of this research is to evaluate and investigate the relationship between disease severity, disease knowledge and QOL of patients with psoriasis, and assess their knowledge regarding psoriasis and QOL.

## Materials and Methods

### Study Population

This was a cross-sectional multicenter study conducted in the dermatology clinics of Hospital Sultan Haji Ahmad Shah (HoSHAS) and Hospital Tengku Ampuan Afzan (HTAA), two tertiary-care hospitals located in Pahang, Malaysia between January 2019 and January 2020. Patients were eligible to participate in the study if they were diagnosed with psoriasis at least six months prior to recruitment. Patients who were less than eighteen years old, pregnant, and cognitively impaired were excluded from this study.

### Sample Size Calculation

The study was designed to include at least 50 patients to have a 95% confidence interval and power of 80%. This calculation was based on an estimated psoriasis population of 3%<sup>2</sup> and a drop-out rate of 10%.

### Study Design

Data collection was carried out during patients' routine clinic appointments. Written informed consent was obtained from the subjects before recruitment, after which they were given a set of questionnaires to be answered. These included a socio-demographic data collection form, Psoriasis Knowledge Assessment Questionnaire (PKAQ) and Dermatology Life Quality Index

(DLQI) questionnaire. The attending doctor then evaluated and completed the Psoriasis Area and Severity Index (PASI) score for each subject. All forms and questionnaires were then verified by one of the investigators to ensure data completeness and all data were then entered into a database for analysis. A second investigator cross-checked all entries to ensure accuracy during data transfer.

### Measurement of Outcomes

#### Psoriasis Area and Severity Index (PASI)

PASI is a commonly used validated tool to assess the severity of psoriasis.<sup>11</sup> In PASI, the body surface area is divided into four sections: head and neck, trunk, upper extremities and lower extremities. The assessment of severity of the symptoms, namely erythema (redness), induration (thickness) and desquamation (scaling), is performed separately for each region, resulting in a total score ranging from zero to seventy-two. The severity of psoriasis is then categorised based on the total score, giving a three-tier severity of mild (<7), moderate (7-12) and severe (>12).<sup>12</sup> A different disease severity classification compared to the Malaysian Clinical Practice Guidelines for the management of psoriasis vulgaris was used.<sup>13</sup>

#### Psoriasis Knowledge Assessment Questionnaire (PKAQ)

PKAQ is a validated questionnaire to assess the knowledge of study subjects in psoriasis.<sup>14</sup> The questionnaire consisted of twenty-five statements related to psoriasis, including the basic facts (nine items), the triggering factors (five items), the disease process (seven items) and the treatment aspects (four items). Subjects were requested to mark each statement as 'true', 'false' or 'do not know'. A correct response was scored as one, while incorrect and 'do not know' responses were scored as zero. The final possible score ranged from zero to twenty-five. The questionnaire which is available in the English language, was translated to the Malay version for ease of comprehension. Face and content validation were performed by a dermatology pharmacist and a dermatologist with native language background. Cronbach's

alpha tested on ten random samples had a score of 0.595.

#### Dermatology Life Quality Index (DLQI)

The DLQI questionnaire<sup>15</sup> is a self-explanatory, validated questionnaire used to measure patients' QOL affected by skin disease over the past seven days. The questionnaire consisted of ten questions which were categorised into six domains of QOL: symptoms and feelings (question 1 and 2), daily activities (question 3 and 4), leisure (question 5 and 6), work and school (question 7), personal relationships (question 8 and 9), and treatment (question 10). Each question had four possible responses: 'not at all', 'a little', 'a lot' or 'very much', with their corresponding scores of zero, one, two and three, respectively. Patients were only allowed to choose one response for each question. The DLQI was then calculated by summing the scores of all questions, resulting in a final index score ranging from zero to thirty. The higher the index score, the greater the impairment of QOL. The scores were categorised into several bands of ascending impact levels: no effect (DLQI 0-1), small effect (DLQI 2-5), moderate effect (DLQI 6-10), very large effect (DLQI 11-20) and extremely large effect (DLQI 21-30).<sup>16</sup> The questionnaire is available in multiple languages. The Malay and English bilingual version were used in this study. Cronbach's alpha tested on ten samples had a score of 0.784.

#### Statistical Analysis

Descriptive statistics were presented using mean, median, standard deviation (SD), interquartile range (IQR) and percentage, as appropriate. Correlations between PKAQ, DLQI and PASI scores were analysed using Spearman's test. A value of  $p < 0.05$  was considered significant. All analysis was conducted using IBM SPSS Statistics for Macintosh, Version 26.0. Armonk, NY: IBM Corp

#### Ethics Approval

Ethical approval was obtained from the Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia prior to data collection (KKM/NIHSEC/P19-1040(6)).

## Results

### Demographic

A total of 114 subjects participated in this study. The mean age of the study population was  $48.8 \pm 15.15$  (Table 1). The study population was equally distributed among women (50.9%) and men (49.1%). Most of the subjects were Malay (76.3%), followed by Chinese (13.2%), Indian (9.6%) and Indonesian (0.9%). Only five (4.4%) subjects did not have any formal schooling, while thirty-seven (32.5%) subjects attained the highest qualification in education at university level. At the time of the study, a high proportion of the subjects were married (78.1%) and were presently employed (55.3%). The median duration of suffering from psoriasis was 8 years (range 1-59). The most common type of psoriasis encountered was plaque psoriasis (88.6%), followed by pustular psoriasis (4.4%), guttate psoriasis (3.5%), and erythrodermic psoriasis (2.6%). Approximately 1% of subjects had concomitant psoriatic arthropathy.

### Psoriasis Area Severity Index (PASI)

The median PASI score was 4.4 (IQR = 7.7). Majority of the subjects (64%) had mild psoriasis, defined by a PASI score of less than 7, while 20.2% of subjects had severe psoriasis (PASI >12), and 15.8% moderate psoriasis (PASI 7-12) (Table 1).

### Psoriasis Knowledge Assessment Questionnaire (PKAQ)

The mean score for PKAQ was  $14.2 \pm 4.4$ . The lowest score reported was one, whereas the highest was 23. Half of the subjects (50.9%) had the misconception that psoriasis is contagious. In addition to that, 78.1 % of subjects also believed that psoriasis is curable. A majority of the subjects were aware that psoriasis can affect both men and women (93%), can affect the entire skin (88.6%) and joints (55.3%), and can happen at any age (91.2%). More than half of the subjects were able to correctly identify stress (72.8%), certain medications (63.2%) and infection (64%) as triggering factors for psoriasis (Table 2).

However, 55.3% of them did not know that injury to the skin may also trigger the disease. More than half of the subjects were able to correctly identify that psoriasis can affect the nails (63.2%), palms and soles (55.3%), but not the brain (51.8%). Furthermore, most of the subjects (70.2%) were aware that psoriasis was not transmitted through sex and sharing of food. Nevertheless, 57.9% subjects had the misconception that diet restrictions may cure psoriasis. More than two-thirds (70.2%) of the subjects were aware of the possibility of side effects from certain medications used in the treatment of psoriasis. A large proportion of subjects were also aware that moisturizers (87.7%) and oral medications (63.9%) helped treat psoriasis. Conversely, only 39.5% subjects recognised phototherapy as an effective treatment modality (Table 2).

### Dermatology Life Quality Index (DLQI)

The median DLQI score was 7 (IQR = 10), with the minimum score being zero and the maximum was 26. Figure 1 depicts the DLQI score and their respective frequencies within each category, while Figure 2 details the degree of impairment within each domain. Most subjects experienced a moderate impairment to their QOL (Figure 1). In comparison to other domains, the highest number of subjects (43.9%) reported psoriasis as having 'a lot of' to 'very much' effect on their symptoms, feelings, work or school. The least affected domain was 'personal relationships', where 54.4% of subjects were not affected by their disease, while only 1.8% of subjects were extremely affected.

### Correlation between PASI, PKAQ and DLQI

There was a significant association between PASI and DLQI ( $r_s = 0.264, p = 0.004$ ) (Figure 3). A higher PASI score correlated with a higher DLQI score. However, there was no statistical significance between the PASI and PKAQ scores ( $r_s = 0.058, p = 0.542$ ), as well as between DLQI and PKAQ scores ( $r_s = -0.048, p = 0.612$ ).

**Table 1.** Baseline demographics and clinical characteristics of subjects (n=114)

<b>Age</b>	
Mean ( $\pm$ SD)	48.8 ( $\pm$ 15.15)
Range	18-83
<b>Gender</b>	
Male	56 (49.1%)
Female	58 (50.9%)
<b>Race</b>	
Malay	87 (76.3%)
Chinese	15 (13.2%)
Indian	11 (9.6%)
Indonesian	1 (0.9%)
<b>Marital Status</b>	
Married	89 (78.1%)
Single	16 (14%)
Divorced or Widowed	9 (7.9%)
<b>Education Level</b>	
No formal education	5 (4.4%)
Primary education	14 (12.3%)
Secondary education	58 (50.9%)
Tertiary education	37 (32.5%)
<b>Occupational Status</b>	
Employed	63 (55.3%)
Unemployed	51 (44.7%)
<b>Type of Psoriasis</b>	
Plaque	101 (88.6%)
Pustular	5 (4.4%)
Guttate	4 (3.5%)
Erythrodermic	3 (2.6%)
Psoriatic Arthropathy	1 (0.9%)
<b>PASI Category</b>	
Median (range)	4.4 (0-36)
Mild	73 (64%)
Moderate	18 (15.8%)
Severe	23 (20.2%)
<b>Duration of Disease (years)</b>	
Median (range)	8 (1-59)
<b>DLQI</b>	
Median (range)	7 (0-26)
<b>PKAQ</b>	
Median (range)	15 (1-23)

SD: standard deviation; PASI: Psoriasis Area and Severity Index; DLQI: Dermatology Life Quality Index; PKAQ: Psoriasis Knowledge Assessment Questionnaire



**Table 2.** Distribution of responses to each of the items of PKAQ (n=114). The shaded boxes represent the correct response

No	Statements	True	%	False	%	Don't Know	%
1	Psoriasis is contagious.	58	50.9	41	36	15	13.2
2	Psoriasis may begin at any age.	104	91.2	3	2.6	7	6.1
3	Psoriasis can affect the entire skin.	101	88.6	7	6.1	6	5.3
4	Psoriasis affects both men and women.	106	93	3	2.6	5	4.4
5	Psoriasis is a curable disease.	89	78.1	15	13.2	10	8.8
6	The exact cause of psoriasis is known.	33	28.9	21	18.4	60	52.6
7	Psoriasis can be associated with joint pain.	63	55.3	23	20.2	28	24.6
8	Specific food intake or restrictions may cure psoriasis.	66	57.9	24	21.1	24	21.1
9	In psoriasis, skin cells are multiplying too slowly.	40	35.1	38	33.3	36	31.6
10	Injury to the skin may cause psoriasis to appear at that site in persons already having psoriasis.	51	44.7	33	28.9	30	26.3
11	Psoriasis never occurs in the nails.	21	18.4	72	63.2	21	18.4
12	Certain drugs may increase the severity of psoriasis in persons already having psoriasis.	72	63.2	19	16.7	23	20.2
13	Certain infections may increase the severity of psoriasis in persons already having psoriasis.	73	64	8	7	33	28.9
14	Stress plays no role in psoriasis.	17	14.9	83	72.8	14	12.3
15	Psoriasis increases in winter.	16	14	41	36	57	50
16	Having close blood relatives affected with psoriasis determines to great extent whether a person will have psoriasis or not.	55	48.2	30	26.3	29	25.4
17	Psoriasis never occurs in the palms and soles.	29	25.4	63	55.3	22	19.3
18	Psoriasis damage brain.	6	5.3	59	51.8	49	43
19	Psoriasis is transmitted through sharing food.	12	10.5	80	70.2	22	19.3
20	Psoriasis is transmitted among sexual partners.	8	7	80	70.2	26	22.8
21	Photo / light therapy is useful in treating psoriasis.	45	39.5	17	14.9	52	45.6
22	Oral medications are useful in psoriasis.	74	64.9	16	14	24	21.1
23	Certain drugs which are used to treat psoriasis may have side effects.	80	70.2	10	8.8	24	21.1
24	Psoriasis is seen all over the world.	100	87.7	3	2.6	11	9.6
25	Treatment of psoriasis can include moisturizers.	100	87.7	2	1.8	12	10.5

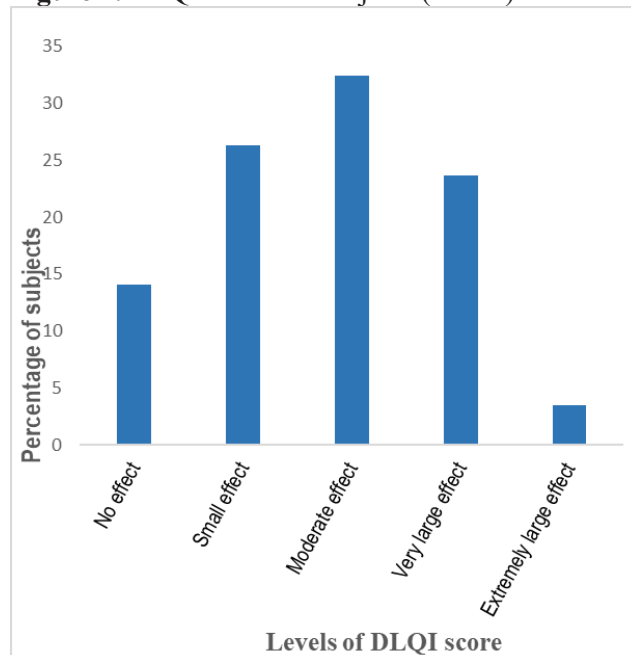
### Discussion

This study demonstrated that the severity of psoriasis significantly affected QOL, with poorer QOL seen among patients with more severe disease. This was in consensus with several local<sup>8,9</sup> and international studies.<sup>17-18</sup> A Taiwanese study of 305 patients found that for every 1-point increment in the PASI score, there was an estimated increase in DLQI by 0.24 points (*p-value 0.0086*). Similar findings were noted when Psoriasis Disability Index (PDI)

was used as a parameter of QOL, with higher PDI scores having a greater impact on QOL, especially among those with higher PASI scores (*p<0.001 and p=0.005*).<sup>19-20</sup> Hence, to minimize the impact of psoriasis on patients' QOL, PASI scores need to be reduced by optimally treating psoriasis.

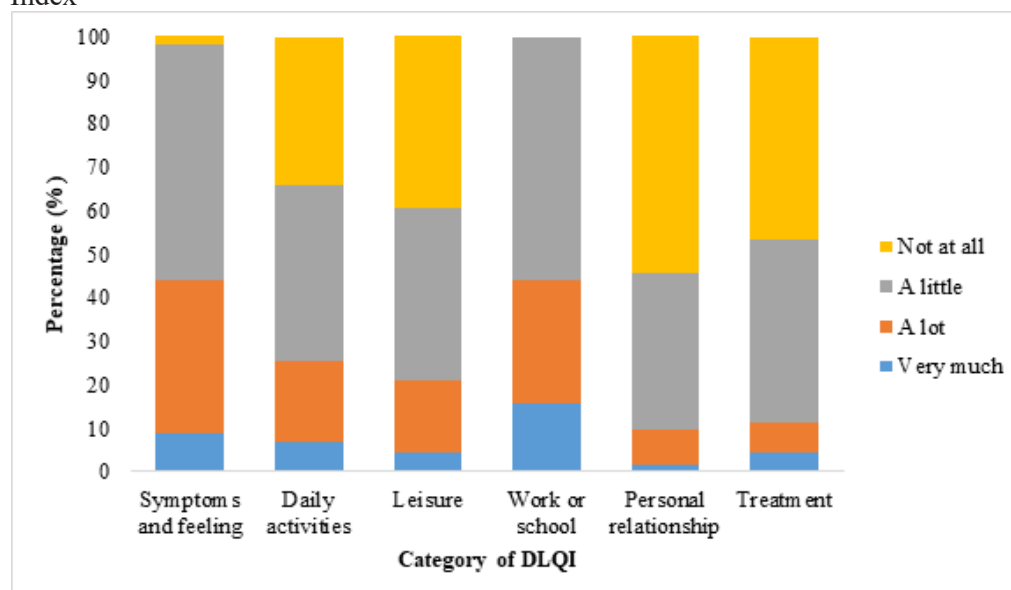
This study also revealed that patients did not have adequate knowledge about psoriasis. In the future, a leaflet about psoriasis should be provided to the newly diagnosed patients. Patients should also be allowed time to ask questions at every clinic visit. A study by Jankowiak et al.<sup>21</sup> found that patients with a higher education level had greater knowledge concerning psoriasis. This may explain the moderately low mean score of PKAQ (14.2) in this study, where a majority of the subjects (67.6%) had secondary education and below. A lack of knowledge regarding psoriasis among patients had also been highlighted in several studies. In a previous study using the same PKAQ by Nagarajan et al<sup>14</sup>, 52% of 200 subjects had inadequate knowledge. The same study discovered that a large number of subjects (49%) did not know that psoriasis was incurable, similar to our study where 78.1% thought psoriasis was curable. An alarming 50.9% of

**Figure 1.** DLQI scores of subjects (n=114)

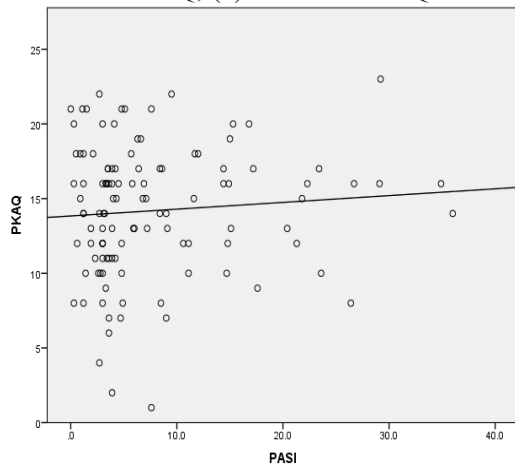


\*DLQI 0-1= No effect. 2-5= Small effect. 6-10= Moderate effect. 11-20= Very large effect. 21-30= Extremely large effect

**Figure 2.** Quality of life impairment in psoriasis patients based on categories of Dermatology Life Quality Index

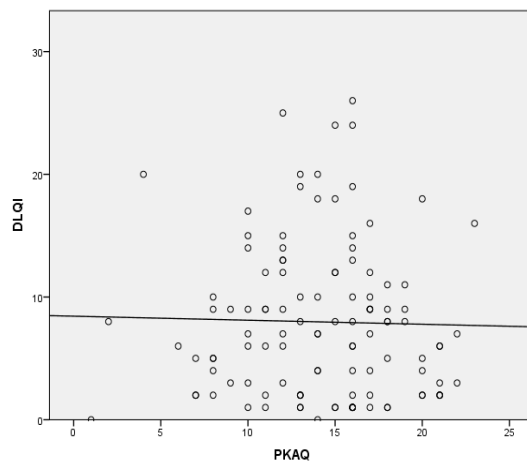


**Figure 3.** Correlation between (a) DLQI and PKAQ; (b) PASI and PKAQ; (c) PASI and DLQI



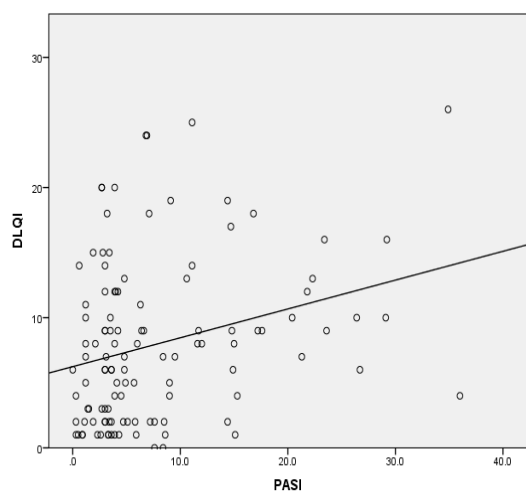
*Spearman's correlation = -0.048 (p = 0.612)*

**(a)**



*Spearman's correlation = 0.058 (p = 0.542)*

**(b)**



*Spearman's correlation = 0.264 (p = 0.004)*

**(c)**

subjects had the misconception that psoriasis was contagious. These findings highlight the need for proper patient education by healthcare providers to clarify patients' doubts and reduce misconceptions about the disease. Most subjects (72.8%) were able to identify stress as a trigger, similar to a study by Wahl et al<sup>22</sup> who used a 49-item Psoriasis Knowledge Questionnaire (PKQ). They also found that more than half of the study subjects did not know that sunburn and infections could trigger psoriasis. Meanwhile in our study, 55.3% of subjects could not identify injury as a triggering factor. Equally alarming was that 57.9% of our study subjects wrongly believed that diet restrictions could cure psoriasis, which poses a risk of malnutrition among them. This prevalence is much higher compared to another study which documented a misconception of only 28.5%.<sup>14</sup> With regards to treatment, a majority (60.5%) of subjects were unable to identify phototherapy as one of the treatment modalities of psoriasis. Nagarajan et al<sup>14</sup> also found that 85% of their subjects did not know about phototherapy being used to treat psoriasis. One possible reason for our finding could be that the majority of our subjects had mild disease (64%), which did not necessitate phototherapy as a treatment option.

Most of our subjects' QOL was moderately affected by psoriasis, as evidenced by their DLQI scores. This is similar to another local study by Nyunt et al,<sup>8</sup> involving 223 patients, with a median DLQI score of 7 (IQR = 7). In comparison, another study from Taiwan involving 480 patients had a mean DLQI score of  $9.16 \pm 6.3$ .<sup>23</sup> A closer examination into individual components revealed that the most affected domains were 'symptoms and feelings', and 'work or school', while the least affected domain was 'personal relationships'. This was also consistent with findings from Nyunt et al,<sup>8</sup> Tang et al<sup>9</sup> and Lin et al<sup>23</sup> On the other hand, a study of 72 Mexicans showed that the most impacted domain was 'symptoms and feelings' (157 points), but the least impacted domain was 'school or work' (25 points).<sup>18</sup> Patients' negative feelings may be due to the affected skin areas that were difficult to conceal, thus stigmatization



can ensue.<sup>24</sup> Therefore, patients' self-esteem and perception towards self-body image should also be taken into consideration when managing a patient with psoriasis. Troubling symptoms such as itchiness and pain need to be identified and treated appropriately. The least affected "personal relationships" domain could be due to good psychosocial support and acceptance from the patients' families, partners and community. Our results found no statistically significant relationship between disease severity and knowledge score of psoriasis patients. This is in agreement with a study by Fortune et al.<sup>25</sup> who also did not find any significant association between severity of psoriasis and beliefs held by patients about their condition, measured using the Illness Perception Questionnaire (IPQ). However, two studies by Wahl et al<sup>22, 26</sup> at different periods confirmed that patients with greater disease severity had stronger beliefs about the chronicity, negative consequences and emotional impact of psoriasis, in addition to better baseline knowledge. In comparison to the milder cases, patients with severe disease may be more interested to learn about the disease to have better control over the symptoms. However in our study, patients' knowledge score could be diminished due to factors such as their level of education and treatment modality. This is especially so when only 32.5 % of our patients attended universities and 64% of the cases were mild. Thus, they were unable to identify phototherapy as one of the treatment options.

We also found no significant relationship between knowledge scores and QOL. A study found that patients with more knowledge about psoriasis had a better QOL, since they were less worried about the disease and perceived less severe consequences.<sup>21</sup> Despite the lack of objective evidence in the literature to support the association between knowledge and QOL, there are several studies which have demonstrated an improvement in QOL following an active educational intervention.<sup>10,27-28</sup> Balato et al<sup>27</sup> used mobile phone text messages to send educational information and reminders to patients for a period of 12 weeks, which resulted in an increase in patients' QOL after the intervention

compared to the control group ( $p < 0.05$ ). Bostoen et al<sup>28</sup> created a 12-week educational programme of 2-hour sessions twice a week and showed a significant reduction in the mean DLQI score from 8.4 to 4.4 after the programme. In another study, the researchers used the PDI score to measure QOL before and after a 12-week video-teaching programme, and found a decrease in disability scores from  $15.6 \pm 6.9$  to  $9.9 \pm 5.1$  after 3 months of intervention.<sup>29</sup> These observations highlight that the clinicians' efforts to educate patients translate into positive QOL. However, there might be the potential of observer bias (Hawthorne Effect) in intervention studies. Since educational intervention was not carried out in our study, the effect of knowledge increment on reducing the impact on QOL could not be observed.

This study had a few limitations. The major limitation was that most of the subjects had mild psoriasis. As a consequence, the result may not adequately represent patients with moderate and severe psoriasis. In addition, there was misclassification bias among patients with special sites such as the genitalia, face and palms. They may be wrongly classified as having mild psoriasis since disease severity was based on PASI, and special sites are not considered in PASI calculation. Future research should study the effect of educational intervention towards improving QOL among patients suffering from psoriasis.

## Conclusion

In summary, severe psoriasis was associated with higher impairment in QOL. However, there was no correlation between knowledge and severity of psoriasis, as well as between knowledge and QOL. Future research should quantify the effect of patient education intervention, to investigate if knowledge increment will improve their disease severity and QOL.

## Conflict of Interest Declaration

The author have no conflict of interest to declare.

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