Mental Health Status among Systemic Lupus Erythematosus (SLE) Patients at Tertiary Hospital in Malaysia

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Abstract

Systemic Lupus Erythematosus (SLE) is an autoimmune disease that can affect and cause damage to several human organs such as the skin, kidneys, muscles, joints, lungs, heart and brain. Uncontrolled relapses in SLE patients can lead to death. SLE patients and their families also face difficulties due to lack of information about the disease. Therefore, studies focused on the psychological aspects such as symptoms of anxiety and depression among SLE patients is still needed in Malaysia. Thus, this study investigated the psychological status of SLE such as the occurrence of anxiety and depression in SLE patients and its associated factors. A cross-sectional study using the purposive sampling was carried out at University Kebangsaan Malaysia Medical Centre (UKMMC). Hospital Anxiety and Depression Scale questionnaires were used to occurrence of anxiety and depression respectively. Out of 150 SLE patients participated, 46.6% had anxiety while another 33.3% experienced severe depression. Anxiety and depression were significantly correlated with socio-demographic factors such as gender (p = 0.006, p = 0.003 respectively), level of education (p = 0.028, p = 0.003 respectively), and monthly income (p = 0.008, p = 0.001 respectively). Overall, socio-demographic factors have important influence on the occurrence of anxiety and depression in patients with SLE. Mental health issue among SLE patient in Malaysia should be taken into consideration by health care provider especially by medical social worker.

Keywords: anxiety, depression, mental health, systemic lupus erythematosus, SLE, social work

Introduction

Systemic Lupus Erythematosus (SLE) is an autoimmune disease in which a person’s immune system does not function normally to the extent it attacks the body’s organs (Kluwer, 2008). According to the Malaysian SLE Association (2012), more than 10,000 patients with SLE were detected in Malaysia over the past 30 years, and almost half of the patients with SLE in Malaysia have yet to be traced. In general, SLE affects 1 in 200 to 2,000 of the world’s population and the disease more often affects female than male patients with a ratio of 9:1 (Schur, 1996).

However, studies related to quality of life and psychosocial aspects of SLE patients were rarely conducted especially in Malaysia (Chin, Cheong & Kong, 1993). Psychosocial development is the concept of linking the psychological relationship between environment and behavior (Feldman, 2010). A mentally healthy person is defined by WHO as someone who is able to realize his potential, to
confront stress in life, to work productively, and to produce and contribute positively to the community (WHO, 2014). Mental health problems were known to have a strong relationship with the decline of physical health in a person (Royal College of Psychiatrists London, 2010).

Stoll, Kauer, Büchi, Klaghofer, Sensky & Villiger (2001) found that there was an association of depression among SLE patients using Hospital Depression Anxiety Score (HDAS–D). Surprisingly, Rynalmma Buji, Fong, Murad, Jaaafar, Said, Mohd, Shah, Hussain, Jamal & Thambu (2016) reported that suicidal ideation of patient with SLE in Malaysia was significantly associated with their current depressive disorder and severity of depression. Emphasis on psychological aspects is crucial because mental health problems interfere with chronic patients’ quality of life (Marks, 2003). Mental health problems could interfere with a patient’s compliance towards treatment and the ability and confidence of patients with chronic illness (Iverson, Sawyer, McCracken & Kozora, 2001). Thus, this study is to critically assess the collection of the important information of the SLE patient such as socio-demographic characteristic and mental health status that may contribute to improve the provider’s quality of health care intervention.

Methods

By using sample size manual calculation by Kish (1965) a total of 150 SLE patients consist of 26 males and 124 females involved in this study. This study utilized the cross-sectional method with purposive sampling technique. Patient aged over 18 years’ old and Malaysian citizens were eligible to become respondents in this study while patient who underwent treatment less than six months and had mental illness history were not eligible to become respondents in this study. HADS test tool were used to screen the level of anxiety and depression. Previous studies that used HADS, which is a common psychological screening tool, had shown acceptable psychometric properties in measuring the characteristics of a person (Mykletun, Stordal & Dahl, 2001). HADS is a self-report scale consisting of 14 items on a Likert scale ranging from 0 to 3. The total score for each subscale that corresponds to anxiety and depression has a possible score from 0 to 21. This total score is categorized into three levels i.e. normal level (0–7), intermediate level (8–10), and incidence level for anxiety and depression (11–21) (Langosch, Rand, Ghosh, Shama, Tench, Stratton, D’Cruz, Trimble, Barrett & Ring, 2008; Nowicka-Sauer, Czuszynska, Majkowicz, Smolenska, Jarmoszewicz, Olesinska & Siebert, 2012; Zigmond & Snaith, 1983). A person may be experiencing anxiety and depression if the total HADS scores obtained is over 11 because it has significant effect on anxiety and depression (Langosch et al. 2008).

Sensitivity and specificity measure for depression were both at 90%, and sensitivity and specificity for anxiety were 95% and 90% respectively (Zigmond & Snaith, 1983). According to Mak and colleague, HADS is more sensitive in measuring level of anxiety and depression in patients without psychiatric problems (Mak, Tang, Chan, Cheak, & Ho, 2011). HADS was translated into Malay language and was used by a number of researchers in their studies (Fariza, 2003; Hasanah, Zaliha, & Mahiran, 2011; Yee & Lin 2011). Fariza (2003) found in her study that sensitivity and specificity of HADS depression was 92.3% and 90.8% respectively, sensitivity and specificity of HADS anxiety was 90% and 86.2% respectively. Yusoff, Low & Yip (2011) found that the alpha value was 0.88 for anxiety and 0.79 for depression. However, this test is only a tool to screen anxiety and depression experienced by someone and not to measure whether a person really has somatic symptoms (Gordon & Clarke, 1999).

Since the data is not normally distributed, non-parametric test was used in this study. This study has been approved by Secretariat for Research and Innovation, University Kebangsaan Malaysia Medical Centre under code FF-228-2011. In addition, the data collection application has also been approved by Nephrologists, Dialysis and SLE Unit by November 2011 until May 2012. Chi-square test and spearman test has been used to look at the relationship between socio-demographic factors with the anxiety and depression level and scores.
Results

Mean age and median age of the SLE patients involved in this study was 30 years and 29 years, respectively, with an age ranging from 18 to 53 years of age. Majority of the SLE patients were female (82.7%). Their ethnic distribution was 46.0% Malay, 34.7% Chinese, 16.7% Indian and 2.6% other ethnic. More than half (58.0%) of them were unmarried, 35.3% were married and 6.7% were widower. Majority of them (66.7%) studied until secondary school, 30.7% went to college/university and only 2.6% completed primary school level. Majority of them were working (64.0%), 18.7% were students and 17.3% were unemployed. Around 37.3% of respondents had their income level that was less than RM1,000, 12.0 % had income between RM1,001 – RM2,000, 25.3% had income between RM2,001 – RM3,000, 20.0% had income between RM3,001 – RM4,000, 4.7% had income between RM4,001 – RM5,000 and 0.7% had income of more than RM5,000. Six percent of respondents were diagnosed to have SLE for less than 1 year, another 18.7% have SLE for 1-2 years, 12.7% have SLE for 2-3 years, 24.7% have SLE for 3-4 years, while 16.7% have SLE for 4-5 years and 21.2% were diagnosed to have SLE for more than 5 years. Around 57.3% respondents resided in the urban area while 42.7% respondents were from the rural area.

Table 1 indicated that SLE patients with the highest level of anxiety was 70 (46.7%), followed by the normal level of anxiety that was 46 (30.7%) and a total of 34 patients had an intermediate level of anxiety (22.7%). While patients with intermediate level of depression are the highest that is 50 (34%), followed by the occurrence high level of depression that is 50 (33.3%) and a total of 49 patients are normal level of depression (32.7%).

Table 1: Anxiety score level

| Anxiety (level)       | n (150) | %    |
|-----------------------|---------|------|
| Normal                | 46      | 30.7 |
| Intermediate          | 34      | 22.7 |
| Occurrence            | 70      | 46.6 |
| Depression (level)    |         |      |
| Normal                | 49      | 32.7 |
| Intermediate          | 51      | 34   |
| Occurrence            | 50      | 33.3 |

Table 2 shows that there was no significant relationship between age and anxiety score with p= 0.396 and also there was no significant relationship between age and depression score with p= 0.345. Table III showed the relation between gender, education level and income with level of anxiety were significant (p < 0.05). The remaining variables were not significantly related to level of anxiety (p> 0.05).

Table 2: Relationship between age with anxiety and depression scores

| Anxiety       | r    | p   |
|---------------|------|-----|
| Age           | -0.070 | 0.396 |

| Depression    | r    | p   |
|---------------|------|-----|
| Age           | -0.078 | 0.345 |

*p significant when p <0.05 using the spearman test
Table 3: Relationship between socio demographic factors and level of anxiety

| Socio demographic Factors | Occurrence Level (%) | Intermediate Level (%) | Normal Level (%) | x^2   | P     |
|---------------------------|----------------------|------------------------|------------------|-------|-------|
| Gender                    |                      |                        |                  |       |       |
| Male                      | 19(73.1)             | 1(3.8)                 | 6(23.1)          |       |       |
| Female                    | 51(41.1)             | 33(26.6)               | 40(32.3)         | 19.207| 0.006*|
| Ethnic                    |                      |                        |                  |       |       |
| Malay                     | 30(43.5)             | 16(23.2)               | 23(33.3)         |       |       |
| Non-Malay                 | 40(49.4)             | 18(22.2)               | 23(28.4)         | 0.590 | 0.745 |
| Marital Status            |                      |                        |                  |       |       |
| Not Married               | 48(49.5)             | 22(22.7)               | 27(27.8)         |       |       |
| Married                   | 22(41.5)             | 12(22.6)               | 19(35.8)         | 1.185 | 0.553 |
| Education Level           |                      |                        |                  |       |       |
| Low                       | 54(52)               | 25(24)                 | 25(24)           |       |       |
| High                      | 16(34.8)             | 9(19.6)                | 21(45.7)         | 8.684 | 0.028*|
| Income (monthly)          |                      |                        |                  |       |       |
| RM0-RM3000                | 59(52.7)             | 26(23.2)               | 27(24.1)         |       |       |
| >RM3000                   | 11(28.9)             | 8(21.1)                | 19(50)           | 9.686 | 0.008*|
| Duration suffering with the disease |            |                        |                  |       |       |
| 6 months-3 years          | 28(50)               | 14(25)                 | 14(25)           |       |       |
| > 3 years                 | 42(44.7)             | 20(21.3)               | 32(34)           | 1.363 | 0.506 |
| Occupation                |                      |                        |                  |       |       |
| Employed                  | 40(41.7)             | 22(22.9)               | 34(35.4)         |       |       |
| Unemployed                | 30(55.6)             | 12(22.2)               | 12(22.2)         | 3.398 | 0.183 |
| Residence                 |                      |                        |                  |       |       |
| Urban                     | 37(43)               | 22(25.6)               | 27(31.4)         |       |       |
| Rural                     | 33(51.6)             | 12(18.7)               | 19(29.7)         | 1.364 | 0.506 |

*p significant when p <0.05 using the Chi-square test

The chi-square test results showed significant relationship between gender, education level and income with level of depression (p < 0.05) as shown in Table 4. Other factors were not significantly related to the level of depression (p > 0.05).

Table 4: Relationship between socio demographic factors and level of depression

| Socio demographic Factors | Occurrence Level (%) | Intermediate Level (%) | Normal Level (%) | x^2   | P     |
|---------------------------|----------------------|------------------------|------------------|-------|-------|
| Gender                    |                      |                        |                  |       |       |
| Male                      | 16(61.5)             | 4(15.4)                | 6(23.1)          |       |       |
| Female                    | 34(27.4)             | 47(37.9)               | 43(34.7)         | 11.597| 0.003*|
| Ethnic                    |                      |                        |                  |       |       |
| Malay                     | 21(30.4)             | 23(33.3)               | 25(27.8)         |       |       |
| Non-Malay                 | 29(35.8)             | 28(34.6)               | 24(29.6)         | 0.836 | 0.658 |
| Marital Status            |                      |                        |                  |       |       |
Discussion

Mean age and median age of the SLE patients involved in this study was 30 years and 29 years with a range from 18 to 53 years old age. Meanwhile study that has been conducted by Said, Shudim, Mohamad, Shaharir, Tong & Ali (2016) in Malaysia found that the median age of SLE patients is 28 years old. A study by Fatnoon, Azarusman & Zainal (2008) at the Hospital Universiti Sains Malaysia (USM), found that 50.8% of SLE patients were 21 years old. The reason could be that SLE can affect anyone, particularly women who are between the ages of 15 to 45 years (Kong, 2009). The results indicated that the number of female respondents was higher than the number of male respondents with a ratio of 4.8:1. This finding was consistent with those of Al-Rayes, Al-Swailem, Arfin, Sobki, Rizvi & Tariq (2007) who found that the gender ratio of respondents involved in their study in Saudi Arabia was 4.4:1. While study by Said et al. (2016) found that the gender differences that was involved in their study was at a ratio of 14:1. The majority of respondents in this study were Malays (46%), similar to results by Chin et al. (1993) who also found that the majority of respondents in their study were Malays (45%) while study by Said et al. (2016) also found that majority of patients in their study were Malays (66.7%). This finding was inconsistent with those of Mak et al. (2011) in Singapore who found that most of the respondents were Chinese (70%). In terms of marital status, this study found that the majority of respondents were single (58%), and thus supports the assumptions that delayed marriage had a strong relationship with chronic illness because chronic diseases may make a person feel inferior in terms of finding a life partner (Johnson, 1985).

The majority of the respondents had low-income with 37% reporting of a monthly income up to RM3,000.00. Physical disorders of SLE patients can interfere with their daily activities including their job commitment as they have to quit or they had termination of employment. None of the respondents were uneducated and the majority of them (66.7%) had secondary school education. We believe this is because under the Malaysian Law, specifically Part II clause 12, which stated that, it is the right of each Malaysian citizen to formal education.

The majority of the respondents had SLE for duration of 3-4 years. This finding was almost similar to a previous study conducted in South India by Robert and his colleague (Robert, Sunitha & Thulaseedharan, 2006). However, the finding is contradicted with the findings by Said et al. (2016),
when they found that the disease duration of patients who were involved in their study was 9.3 years. When it comes to employment, the majority of the respondents were working in the private sector. This is not surprising due to the fact that government transformation programme for private sector which requires private companies to use large number of highly skilled employee (NEAC, 2010). Finally, in terms of residency, 57.3% of the respondents were from the urban area and 42.7% were from the rural area. Because developments in treatment of diseases were currently growing rapidly in University Kebangsaan Malaysia Medical Centre (UKMMC), many patients regardless of rural or urban areas were referred to UKMMC (Kong, 2009).

This finding is parallel with Figueredo-Braga, Cornaby, Cortez, Bernardes, Terroso, Figueredo, Mesquita, Costa, & Poole (2016) that found 40% of patients had high level of depression and 47% of patients had high level of anxiety. Comparing the prevalence of anxiety and depression based on this study with findings by Chin and friends (1993), who studied a sample of 79 SLE patients in UKMMC, draws mixed results i.e. the prevalence of anxiety was higher in this study (46.6%) as oppose to study by Chin et al. (1993) (7.6%). On the other hand, both the prevalence of anxiety and depression were consistent with the findings by Brey and colleague in the United States (Brey, Holliday, Saklad, Navarrete, Hermosillo-Romo, Stallworth, Valdez, Escalante, Del Rincón, Gronseth, Rhine, Padilla & McGlasson, 2002).

Previous studies have demonstrated that mental health problems in SLE patients could be attributed to the above-mentioned factors and by various other studies (Kong, 2009; Manson & Rahman, 2006; Kluwer, 2008; Zhang, Fu, Yin, Zhang & Shen, 2017) who also reported that the prevalence of depression and anxiety was high among adult SLE patient. Health care provider has to note a link between patients with SLE with a mental health issue so that intervention towards the patient may improve mental healthcare for people who living with SLE (Knight, Vickery, Fiks & Barg, 2015).

This study found no significant relationship between age with anxiety and depression and therefore supports the findings by previous studies carried out in other countries (Bachen, Chesney & Criswell, 2009; Beckerman, Auerbach & Blanco, 2011; Nery, Borba, Hatch, Soares, & Neto, 2007; Stoll et al. 2001; Figueredo-Braga et al. 2016). However, Mak and friends found a significant relationship between age with both of anxiety and depression in Singapore (Mak et al. 2011).

This study found a significant relationship between gender with both anxiety and depression in which male patients experienced more anxiety and depression than female patients did. Green and friends noted that young men are at more risk of experiencing mental health problems (Green, McGinnity, Meltzer, Ford & Goodman, 2005). It has also been found in a study done by Ganes, Khem & Kapil (2016) that females were well adjusted than males. Mckeown & Clarke (2004) reported that most men were reluctant to seek help and support when they have health problems, including mental health problems. Bertera (2005) and Mak et al. (2011) previously found this relationship, but their results also indicated that female patients experienced more anxiety and depression than male patients did.

This study also found no significant correlation between ethnic and prevalence of anxiety and depression. These results were consistent with the results of other studies (Beckerman et al. 2011; Korova, Arciniegas, Zhang & West, 2007). However, the results of this study were not in line with the findings by Mak et al. (2011) who found that the prevalence of anxiety and depression were higher among the Singapore Indians. We believe the similarity in the culture among different Malaysian ethnic groups contribute to the non-significant relationship.

Likewise, no significant relationship between marital status with prevalence of anxiety and depression was found in this study. This result is consistent with the findings by Bachen et al. (2009), but do not support the findings by Mak et al. (2011) who found that more widow or widower respondents were experiencing anxiety and depression.

The result shows that there is significant relationship between level of education with anxiety and depression. The results were also similar to the results with studies conducted in the United States who found that respondents with low levels of education were more vulnerable to anxiety and depression.
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(Auerbach & Beckerman, 2011; Bertera, 2005). This occurs because low level of education could contribute to a poor lifestyle and lack of knowledge on good psychosocial development, which will then lead to mental health problems (Patel & Kleinman 2003). Consistent with other studies, this study found a significant relationship between income and prevalence of anxiety and depression (Bachen et al. 2009; Bertera, 2005; Mak et al. 2011).

However, others had suggested that people with low level of income generally have communication problems with their spouse and individuals around them (Sturm & Grasenz, 2002), while individuals with high income were sometimes pressured to keep up their status and standard of living (Paskov, Gerxhani, Herman & Werfhorst, 2013). Figueredo-Braga et al. (2016) also reported that healthy people tend to have more education and demonstrate lower level of unemployment compared to people who are living with SLE. Nevertheless, the results of this study were more in line with those of Sturm & Grasenz (2002) studies.

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The finding indicating the link between disease duration and prevalence of anxiety and depression was similar with previous studies (Bachen et al.; 2009; Bertera, 2005; Stoll et al. 2001). Consistent with the findings of Beckerman et al. (2011) this study also revealed no significant relationship between employment and prevalence of anxiety and depression. However, these findings differ with those of Auerbach and Beckerman (2011), who found that unemployed people were at higher risk of developing psychological disorders.

Conclusion

Mental health status such as anxiety and depression are influenced by socio-demographic characteristic (Figueredo-Braga et al. 2016). Therefore, research on the influence of socio-demographic characteristic towards psychosocial status should be carried out in SLE patients as this will further encourage determining and identifying the real needs of these patients. Through this initiative, it is hope that the delivery of accurate information about the disease would be given through psycho education to the patients and their families.

As a conclusion, physicians should refer patients newly diagnosed with SLE disease to the Department of Medical Social Work. Social worker should facilitate the demographic characteristics of SLE patients to have better access towards information of the case referred. The results of this study have shown some information about socio-demographic characteristic and mental health status among SLE patients in which the information has the potential to be a baseline data to help health care provider especially medical social worker to understand the SLE patients better and give them the right intervention. Medical social workers as a person who provide psychosocial support should improve their skills and knowledge about the SLE disease through research and development. This study also found that mental health issue among SLE patient in Malaysia should be taken into consideration by health care provider especially medical social worker.
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