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SOCIAL SUPPORT AMONG SYSTEMIC LUPUS ERYTHEMATOSUS (SLE) PATIENT IN MALAYSIA

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Abstract: This research aims to look at the social support available for the Systemic Lupus Erythematosus (SLE) patient and its relationship with socio-demographic and psychological factors in Universiti Kebangsaan Malaysia Medical Center, Kuala Lumpur, Malaysia. A total of 150 patient with SLE who are seeking treatment have filled the questionnaires distributed and consist of 26 male patients and 126 female patients with a ratio (1:4.8). A cross sectional study using the convenience sampling was conducted where the MSPSS questionnaires (Multidimensional Scale of Perceived Social Support) was used to measure the social support scores while Hospital Anxiety and Depression (HADS) was used to measure the psychological aspect obtained by patient. The social support overall showed a significant relationship only with the monthly income. Family social support were significantly related to ethnicity and income, friends social support seen to have a significant relationship with education and income, where else there is no significant relationship between significant other social support with demographic characteristics of patient with SLE. There result showed that there was a negative strong significant relationship between social support overall, social support from family, social support from friends and social support from significant other with score of anxiety and depression. All the test results showed $p<0.000$ and $r>-0.6$. This means that there is a significant relationship between social support, family social support, friend social support and social support of special friend with the occurrence of anxiety and depression experienced by patients with SLE.

Keywords: social support, demographic characteristics, systematic lupus erythematosus, MSPSS, SLE patient

INTRODUCTION

Systemic Lupus Erythematosus (SLE) is an autoimmune disease where a person's immune system will be disturbed, and antibodies are produced against own organs and tissues (Wallace & Hanh 2002). There are several symptoms of SLE such as prolonged fever, weight loss, joint pain, skin rash especially in parts exposed to sunlight, mouth sores, swelling of the face and legs, hair loss and it attacks organs like the skin, heart, lungs, and kidney (Abramovits 2008). Besides that, SLE can be fatal if it relapse and goes untreated (Kong 2009). Besides treatment, more time should be devoted for counseling and educating the SLE patient and their families about the disease and the importance of compliance in order to control this disease (Kong 2009). According to Schur (1996) in general, SLE can attack one in 200 to 2,000 people from the world population and this disease often affects more female than male with a ratio of 9:1. Systematic Lupus Erythematosus (SLE) has been identified by Moritz Kaposi in Vienna Medical School as prolonged fever, weight loss, arthritis, anemia and swelling of the lymph glands and Sir William Osler had determined that it attacks the heart, lungs and kidneys of patients with SLE (Abramovitz 2008). Based on previous studies that were conducted, the prevalence of SLE in Malaysia is 43/100,000 people (Chin, Cheong Kong 1993). The Malaysian SLE Association argues that there are many individuals who are suffering from SLE, but yet to be diagnosed and get proper treatment for SLE as these diseases is difficult to be diagnosed (Malaysian SLE Association 2012). Study on SLE patient's psychosocial very seldom conducted in Malaysia (Chin, Cheong Kong 1993; Malaysian SLE Association 2012). Manson also noted that the study of the psychosocial experiences suffered by patients with SLE in the United States is also fewer given priorities Manson, Rahman 2006). Auerbach & Beckerman (2011) and Wallace (2005) states that almost all SLE patients faces many difficulties and this cause negative impact on their psychosocial condition.

According to Asmawati (2004) social relation have good implication on mental and physical health, as via social relation one is able to obtain social support. Social support is identified as a platform for a person to be loved, cared for, respected, and appreciated and it also function as a major communication network among human (Kim et al., 2008). Social support derived from spouses, family members, friends and relationship with the

surrounding community. According to Feldman (2010) human relations can also help a person to develop coping strategies towards stress because many previous studies have shown that social support is an element that can provide information, care system and help individuals to maintain low pressure thus can help in dealing with stress very well. Atkinson et al. (1986) stated that social support commonly able to affect the life stress experienced by a person. The relationship between social support and health has received considerable attention in the field of behavioral medicine and psychological health (Mazzoni & Cicognani 2011). Social support is considered an important factor for patients with chronic illness such as cardiovascular, neuroendocrine diseases, and patients with immune disorder. SLE is also an immune disease and some of the SLE patients also suffer from rheumatic problems (Uchino 2006). Pedersen also noted that social support can determine the psychological status and can influence the mortality rate of chronic illness patient (Pedersen et al. 2009). Ishikura et al. (2001) stated that human relations among family members are likely to be useful for an early treatment or prevention to a variety of mental illness.

RESEARCH METHOD

This study was conducted on 150 SLE patients who are undergoing treatment at the Universiti Kebangsaan Malaysia Medical Centre (UKMMC), Kuala Lumpur, Malaysia in 2012. HADS test is one of the commonly used psychological tool to monitor the occurance of anxiety and depression. Previous studies show the HADS gives consistent results in measuring the psychometric nature of a person (Mykletun, Stordal & Dahl 2001). This test consists of 14 items that consists of questions that can show the scores of anxiety and depression scores ranging from 0 to 21. This tool usess Likert scale with a score of 0 to 3 and the total score is divided into three levels, namely score of 0 to 7 is considered as the normal level, 8 to 10 is considered as the boundary level and 11 to 21 is considered as the incident level of anxiety and depression (Sauer et al. 2012; Langosch et al. 2008; Zigmond & Snaith 1983). A person may be experiencing anxiety and depression if the total score of HADS acquired by someone is over 11 because this has significance influence with the anxiety and depression disorder (Langosch et al. 2008).

Sensitivity and specificity scale for depression are .90 and .90 respectively, while the Sensitivity and specificity scale for anxiety are .95 and .90

respectively (Zigmond & Snaith 1983). HADS found to be more sensitive to measure the levels of anxiety and depression in people who do not have any psychiatric problem (Mak et al. 2010). This test tool has been translated into the Malay language in Malaysia and used by many researchers (Hasanah, Zaliha, & Mahiran 2010; Yee & Lin 2011). Fariza found that sensitivity and specificity for depression was 92.3% and 90.8% respectively while for the anxiety is 90% and 86.2% respectively[19]. Yusoff et al. found that alpha value in their study was 0.88 for anxiety and 0.79 for depression (Yusoff, Low & Yip 2011). However, this test is only a tool used to screen the incident level of anxiety and depression experienced by someone and it is not to determine whether a person has the somatic symptoms (Bjelland et al. 2002).

Social support data were measured using test tools known as the Multidimensional Scale Percieved Social Support (MSPSS) (Zimet et al. 1988). There are few elements in this test tool where the social support is divided into three categories namely support from family, friends, and special friend. These testing tool had been given to patients with SLE and presented with the questions which was answered by using the Likert scale of 1 indicating strongly disagree to 7 indicating strongly agree. This test tool consists of 12 questions. Cheng & Chan, Ng et al. and Teoh & Tam found that this questionnaire using a continuous score, where a high total of mean indicates a high social support scores (Cheng & Chan 2004; Ng et al 2011; Teoh & Tam 2008). Social support research conducted by Avicenna & Rafaei showed that the reliability rate for MSPSS in chronic patient is between 0.85 to 0.91 where else the reliability rate for the Malay language version found by Rizwan and Syed (2010) and Ng et al. (2012) is 0.86 and the alpha value is 0.86 as well .

RESULTS

Table 1 show overall median score for social support (SS) is 57 with IQR range of 48-68. There are three categories in social support scores namely family social support (SSK), friends social support (SSR) and special friend social support (SST) with the median 24 (IQR range 20-24), 16 (interquatile range 16-20) and 19 (IQR range 16-21.3) respectively. All social support scores are high except for social support of friends.

Table 1 Social support score

Social Support Characteristic	Median	IQR Range
Social Support (SS)	57	48-68
Family Social Support (SSK)	24	20-24
Friends Social Support (SSR)	16	16-20
Special Friend Social Support (SST)	19	16-21.3

Table 2 shows that there is no significant relationship between age and social support as the result of Spearman Correlation test (r^2) showed that the p value = 0.414. Relationship between age and family social support, friends social support and special friend social support also showed no significant relationship as the Spearman Correlation test conducted shows the p value as 0224, 0.440 and 0.499 respectively.

Table 2: Relation between social support and age

Variable	SS		SSK		SSR		SST	
	r	p	r	p	r	p	r	p
Age	-0.067	0.414	-0.1	0.224	-0.64	0.440	-0.056	0.499

*p significant when p <0.05 using the Spearman Correlation (r^2) test
* SS: Social support, SSK: Family social support, SSR: Friends social support, SST: Special friend social support

This study uses the non-parametric analysis because all the data are not normal as when Kulmogrof tests performed showed a significant p value <0.05 for each instrument.

Table 3, shows there is a significant relationship between the level of anxiety with social support as the one-way Kruskal-Wallis test showed the p value < 0.05 (p= 0.001).

Table 3: Relation between level of anxiety and social support

Factor	Median Normal Level	Median Boundary Level	Median Incidence Level	IQR Range	z	p
Social Support	72	56	48	48-68	82.19	0.001*

*p significant when p <0.05 using the one-way Kruskal-Wallis te

Table 4, shows there is also a significant relationship between the level of depression with social support as the one-way Kruskal-Wallis test showed the p value < 0.05 (p= 0.001).

Table 4: Relation between level of anxiety and social support

	Depression					
Factor	Median Normal Level	Median Boundary Level	Median Incidence Level	IQR Range	z	p
Social Support	72	56	48	48-68	78.59	0.001*

*p significant when p <0.05 using the one-way Kruskal-Wallis test

Table 5, shows that there is a significant relationship between family social support, friends social support and a special friend social support with anxiety and depression where a one-way Kruskal-Wallis test shows the same p value < 0.05 (p = 0.001) respectively

Table 5: Relationship between level of anxiety and depression of family social support, friends social support and special friend social support.

	Anxiety						Depression					
Factor	Median Normal Level	Median Boundary Level	Median Incidence Level	IQR Range	z	p	Median Normal Level	Median Boundary Level	Median Incidence Level	IQR Range	z	p
SS Family	24	20	20	20-24	55.756	0.001*	24	20	20	20-24	78.592	0.001*
SS Friends	24	16	13.5	16-20	70.518	0.001*	24	16	12	16-20	67.067	0.001*
SS Special Friend	24	20	16	16-21.3	67.837	0.001*	24	18	15	16-21.3	63.918	0.001*

*p significant when p <0.05 using the one-way Kruskal-Wallis test
SS:Social Support

Table 3 shows there is a significant relationship between income and social support overall as the Mann-Whitney test conducted show the p value as 0.009. Other variables are not significant as their p values are above 0.05 (p significant when p <0.05).

Table 3 Relation between social support and sociodemographic factors

	Social Support Overall			
Variable	**Median**	**IQR Range**	**Z**	**P**
Gender				
Male	60			
Female	56	48-68	-0.384	0.701
Ethnic				
Malay	58			
Non Malay	56	48-68	-0.511	0.609
Marital Status				
Bachelor	58			
Married	56	48-68	-0.572	0.567
Education level				
Low	56			
High	60	48-68	-1.605	0.108
Income (monthly)				
RM0.00-RM3,000.00	50			
RM3,000.00 and above	64	48-68	-2.596	0.009*
Duration suffering the disease				
6 months - 3 years	60			
3 years and above	56	48-68	-1.274	0.203
Occupation				
Employed	56			
Unemployed	58	48-68	-0.059	0.953
Residency				
Urban	60			
Rural	56	48-68	-1.122	0.262

*p significant when p <0.05 using the Mann-Whitney test

Table 4 shows there is a significant relationship between ethnicity with family social support as the Mann-Whitney test shows the p value as 0.037. There is a significant relationship between educational level with friends social support where the Mann-Whitney U test show the p value as 0.029. There is a significant relationship between respondents' income with family social support and friends social support as the test of Mann-Whitney shows the p value as 0.019 and 0.001 respectively. Other variables are not significant as their p values are above 0.05 (p significant when p <0.05).

Table 4: Relation between sociodemographic factors with family social support, friends social support and special friend social support

Variable		**Family Social Support**				**Friends Social Support**				**Special Friend Social Support**			
		Median	IQR Range	z	p	Median	IQR Range	z	p	Median	IQR Range	z	p
Gender													
	Male	23.5				16				20			
	Female	24	20-24	-0.237	0.813	16	16-20	-0.123	0.902	19	16-21.3	-0.633	0.526
Ethnic													
	Malay	24				16				19			
	Non-Malay	20	20-24	-2.088	0.037*	16	16-20	-0.520	0.603	19	16-21.3	-0.792	0.429
Marital Status													
	Bachelor	24				16				19			
	Married	24	20-24	-0.281	0.779	16	16-20	-0.346	0.729	20	16-21.3	-1.924	0.152
Education Level													
	Low	23.5				16				18.5			
	High	24	20-24	-1.116	0.264	20	16-20	-2.183	0.029*	20	16-21.3	-0.669	0.503
Monthly Income													
	RM0-RM3000	23				16				18			
	>RM3000	24	20-24	-2.345	0.019*	20	16-20	-3.356	0.001*	20.5	16-21.3	-1.791	0.073
Duration suffering the disease													
	6 months-3 years	24				20				20			
	> 3 years	23	20-24	-1.419	0.156	16	16-20	-0.963	0.273	19	16-21.3	-1.175	0.244

Occupation													
	Employed	23.5				20				19			
	Unemployed	24	20-24	-0.621	0.535	16	16-20	-0.963	0.335	20	16-21.3	-0.476	0.634
Residency													
	Urban	24				20				20			
	Rural	23	20-24	-1.419	0.332	16	16-20	-1.170	0.136	18	16-21.3	-1.050	0.294

*p significant when p <0.05 using the Mann-Whitney test

DISCUSSION

Social support

This study found that majority of respondents exposed to a high level of social support. Culture of helping each other and respect practiced by Malaysians seen as the basis for good social support network for patients with SLE. This study show there is no significant relationship between age and social support. This result is consistent with study conducted by Zheng et al. (2009) and Costa et al. (1999) but not consistent with the study conducted by Alarcón et al. (2002) which found that young age group acquire higher social support than older age for an active socialization process within the community. There is no significant relationship between gender and social support. This result is in contrast to the result of a study conducted by Prezza and Pacilli (2002) who found a significant relationship between gender and social support where male gain greater social support than female. This study found there is no significant relation between ethnicity and social support. This result is different from the findings by a study conducted by Katapodi et al. (2002) and Bertera (2005) their studies in Western countries found a significant relationship between ethnicity with social support. Difference in this study is due to the differences of culture between western countries and Malaysia. It's quite surprising that this study found that marital status also had no significant relationship with social support. Results of this study differs with the result of the study conducted by Prezza and Pacilli (2002) and Alarcón (2002).

This study found there is no significant relation between education level of social support. These result support the findings of a study conducted by Prezza and Pacilli (2002) in Italy but its contrary to the findings of a study conducted by Katapodi et al (2002) Alarcón (2002) and Costa et al. (1999) who found that highly educated respondents have better access for

social support than less educated respondents as with their high-income, it's easy for them to find resources to build social networks. In terms of income, this study found that there is a significant relationship between income and social support where high-income respondents obtain higher social support than low-income respondents. Researchers believe those respondents who earn a higher income able to spend more for other activities such as recreation, travel, and so on with their family, friends, and others.

This study found that there is no relationship between the duration of a patient suffering from these disease and social support. This result supports the finding of a study conducted on patients with chronic illness by Mueller et al. (2005) where there are no differences in social support received by those patients. In terms of occupation, this study found no significant relationship between occupation and social support. This result is inconsistent with the findings of studies conducted by Kroll and Lampert (2009), Roberts et al. (1997) and Liem and Liem (1986) as they found that respondents who are unemployed receive lower social support compared to respondents who are employed. In terms of residency, this study found there is no significant relationship between residency and social support. Results of this study contradicts the findings of studies conducted by Yun et al. (2010), Turcotte (2005) and Gaede (2006) where they found there is a significant relationship between area of resident and social. Rural communities, especially in Malaysia are still practicing collaborative activities that are believed to enhance the helping nature which will build a strong social support network between them (Rahim et al., 2008).

Family social support

As for family social support, this study found that only ethnic and income have a significant relationship with family social support. This finding is in line with the findings by Bertera (2005) who found that there is a relationship between social support and ethnic and income. Maznah (1993) pointed out that many previous studies highlighted that in Malay culture caregiver is defined as an advisor, providing guidance, and guiding towards spirituality.

Friend's social support

As for friend's social support, this study found that education level and income have a significant relationship with the friends social support

where respondents with higher education level will have a higher median score for social support and respondents with higher income obtain a higher social support score too. This finding supports the study conducted by Nieminem et al. (2008) who found that apart from age; only the level of education and income would have a significant relationship with friend's social support.

Special friend social support

As for special friend social support, this study found that all demographic factors have no significant relationship with special friend social support. These result in not consistent with a study conducted by Prezza and Pacilli (2002) who found significant relationship between marital status with special friend social support. A study conducted by Nieminen et al (2008), in Finland show that most demographic factors have no significant relationship with social support.

Results of this study showed that respondents with a higher median score of anxiety and depression have a lower median score for social support. This result is consistent with the studies conducted by Chin et al. to SLE patients in UKMMC where the results of their study also showed a significant relationship between social support with the prevalence of anxiety and depression (Chin, Cheong, Kong 1993). In general, there is indeed a significant relationship between social support with anxiety and depression (Bertera 2005). According to Corrigan & Phelan and Goldberg et al., social support provides a lot of benefits on the psychologic of a person, including in increasing level of self-confidence, improve the functionality of thought, quality of life and help a person to recover from psychological problems (Goldberg, Rollins, Lehman 2003; Pinar et al. 2012). Lack of social support can cause psychiatric symptoms, health problems, and hinders a person from serving the community.

These findings also support the results of a study conducted by Pinar et al. on cancer patients in Turkey that found a significant relationship between social support with anxiety and depression (Pinar et al. 2012). Studies conducted by Ogce et al. (2007) for breast cancer patients also found a significant relationship between social support, social support of friends and social support of a special friend with psychological stress. However, they found that family social support did not have a significant relationship with psychological stress experienced by breast cancer patients (Ogce et

al. 2007). Hipkins also found that an ovarian cancer patient suffers from anxiety and depression associated with social support (Hipkins et al. 2009).

The findings also support thus confirms the social support theory introduced by Lakey and Cronin, (2008). This theory discusses the factors contributing to depression or psychological disorders that occur by stating that life history can influence a person to get psychological problems of depression and researchers assume that life history is the condition of the SLE disease suffered by the respondents.

A high social support will not only help patients with SLE from been attacked by anxiety and depression, but it can help patients with SLE to be in good condition because chronic patients who obtained a high social support from spouse, family members, friends, colleagues or members of the public could contribute to positive clinical effects (Dobson & Dozois, 2008).

CONCLUSION

Healthcare providers in hospitals, including medical social workers, nurses and medical officers should provide a good support system for SLE patients and their families. Through a good support system, information can be delivered to patients, families and communities and via this could increase their level of knowledge and awareness on the disease. Severe physical effects on patients with SLE often causes individuals around them with the impression that SLE is an infectious disease, and this results the SLE patients to feel unease and isolate themselves from family, friends or others. This condition then directly affects their psychological aspects.

The findings of this research have implications and giving a clear guide to social workers especially the medical social worker about the SLE patients in Malaysia specifically in Universiti Kebangsaan Malaysia Medical Centre. This study will not only provide insight on the management of SLE but it can be generalized to other chronic patients as all chronic diseases can inhibit a person's ability to work, socialize and functionality in community, apart from the impact on the patient's own body. Thus, the psychosocial issues are among the major issues faced by social workers and the need to understand the sensitivity of the cases handled is important

as the challenges and obstacles faced by each patient is unique and different.

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Conflicts of Interest
The authors declare no conflict of interest towards the publication of this paper.

Supplementary Materials
Supplementary Materials are added: Figure, appendix table, numbers (link).

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