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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 Systemic Lupus Erythematosus (SLE) patients and its relationship with socio-demographic and psychological factors at Universiti Kebangsaan Malaysia Medical Center, Kuala Lumpur, Malaysia. A total of 150 patients with SLE who are seeking treatment have filled the questionnaires distributed and consisted of 26 male patients and 126 female patients with a ratio (cross-sectional sectional study using 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 the 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 was seen to have a significant relationship with education and income, whereas else there is no significant relationship between significant other social support with demographic characteristics of patient with SLE. Their 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 a significant other with a 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 friends 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 is disturbed, and antibodies are produced against their 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 relapses and goes untreated (Kong, 2009). Besides treatment, more time should be devoted to counselling 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 females than males 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, anaemia 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 are difficult to be diagnosed (Malaysian SLE Association 2012). Studies 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) state that almost all SLE patients face many difficulties and this has a negative impact on their psychosocial condition.

According to Asmawati (2004) social relations have good implications for mental and physical health, as via social relations, 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 functions as a major communication network among human (Kim et al., 2008). Social support is derived from spouses, family members, friends and relationships 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 a 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 is 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 behavioural medicine and psychological health (Mazzoni & Cicognani 2011). Social support is considered an important factor for patients with chronic illnesses such as cardiovascular neuroendocrine diseases, and patients with immune disorders. 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 patients (Pedersen et al. 2009). Ishikura *et al.,* (2001) stated that human relations among family members are likely to be useful for early treatment or prevention of a variety of mental illnesses.

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 tools to monitor the occurrence of anxiety and depression. Previous studies show that HADS gives consistent results in measuring the psychometric nature of a person (Mykletun, Stordal & Dahl 2001). This test consists of 14 items that consist of questions that can show the scores of anxiety and depression scores ranging from 0 to 21. This tool uses the 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 a significance influence on the anxiety and depression disorder (Langosch et al. 2008).

The 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 was found to be more sensitive in measuring the levels of anxiety and depression in people who do not have any psychiatric problems (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 were 92.3% and 90.8% respectively while for anxiety is 90% and 86.2% respectively[19]. Yusoff et al. found that the 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 Perceived Social Support (MSPSS) (Zimet et al. 1988). There are a few elements in this test tool where the social support is divided into three categories namely support from family, friends, and special friends. These testing tools had been given to patients with SLE and presented with 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 used a continuous score, where a high total of mean indicates a high social support score (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 patients is between 0.85 to 0.91 whereas 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 shows 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 a median of 24 (IQR range 20-24), 16 (interquartile 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 the Spearman Correlation test (r^2) showed that the p-value = 0.414. The 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 Kolmogorov 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 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 6 shows a significant relationship between income and social support overall, as the Mann-Whitney test shows 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 6: 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 7 shows there is a significant relationship between ethnicity and 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 shows 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 7: 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 most respondents were exposed to a high level of social support. A culture of helping each other and respect practised by Malaysians is seen as the basis for a good social support network for patients with SLE. This study shows there is no significant relationship between age and social support. This result is consistent with a 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 younger age group acquire higher social support than older

age for an active socialisation process within the community. There is no significant relationship between gender and social support. This result contrasts with the result of a study conducted by Prezza and Pacilli (2002), who found a significant relationship between gender and social support where males gain greater social support than females. This study found that there is no significant relation between ethnicity and social support. This result is different from the findings of a study conducted by Katapodi *et al*., (2002) and Bertera (2005) where their studies in Western countries found a significant relationship between ethnicity with social support. The difference in this study is due to the differences in 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. The results of this study differ from 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 and social support. These results 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 are 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 diseases 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 a*l., (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 that there is no significant relationship between residency and social support. Results of this study contradict the findings of studies conducted by Yun *et al*., (2010), Turcotte (2005) and Gaede (2006) where they found there is a significant relationship between the area of residence and social. Rural communities, especially in Malaysia, are still practising 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 ethnicity 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, ethnicity and income. Maznah (1993) pointed out that many previous studies highlighted that in Malay culture, a 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 a 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 results are not consistent with a study conducted by Prezza and Pacilli (2002), who found a significant relationship between marital status with special friend social support. A study conducted by Nieminen et al (2008) in Finland shows that most demographic factors have no significant relationship with social support.

The 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. on 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 and anxiety and depression (Bertera 2005). According to Corrigan & Phelan and Goldberg et al., social support provides a lot of benefits to the psychologic of a person, including increasing the level of self-confidence, improving the functionality of thought quality of life and helping 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 hinder 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 and anxiety and depression (Pinar et al. 2012). Studies conducted by Ogce *et a*l., (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 and thus confirm 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.

High social support will not only help patients with SLE from being attacked by anxiety and depression, but it can help patients with SLE to be in good condition because chronic patients who obtain high social support from spouses, 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 could increase their knowledge and awareness of the disease. Severe physical effects on patients with SLE often cause individuals around them to have the impression that SLE is an infectious disease, and this results in the SLE patients feeling unease and isolating themselves from family, friends or others. This condition then directly affects their psychological aspects.

The findings of this research have implications and give a clear guide to social workers, especially medical social workers regarding 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 generalised to other chronic patients as all chronic diseases can inhibit a person's ability to work, socialise and functionality in the community, apart from the impact on the patient's own body. Thus, 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 are unique and different.

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Informed Consent

Informed consent was obtained from all subjects involved in the study.

Conflicts of Interest

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

Authors Contribution

In this manuscript, each author contributes equally to the ideas and writing.

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Supplementary Materials

Supplementary Materials are added: Figure, appendix table, numbers.

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