

The Effect of Educational Session of Coping Strategies on the Quality of Life among Systemic Lupus Erythematosus Patients

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Abstract: Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that is common among young females aged 15 to 45 years. The disease characterized by a relapsing and remitting sequence that is life-threatening and affects patients' physical and psychological quality of life. Studies have explored that coping enhance patients' ability to practice fair physical life, improve psychological wellbeing and show more involvement in the social life. The aim of this study was to examine the effect of educating SLE patients about different coping strategies on their quality of life.

Methods: A quasi excremental pre and post-test design was used. A convenience sample of 40 patients with SLE were interviewed in a structured interview. Socio-demographic characteristics, a revised version of Coping Strategy Questionnaire, and SLE QOL questionnaire were used to achieve the study aim. Ethical consideration for all participants were guaranteed throughout the study.

Results: Majority of participants were young females, married, have elementary and high school degree, studying and had no family history of SLE. Diversion, reinterpreting and cognitive coping strategies were more likely to be used among participants and catastrophizing coping was less utilized. There was noticeable improvement in QOL after conducting the coping strategy educational session. The used coping strategies reported statistically significant association with physical activity, social/occupational. Emotions/mood and feelings subscales of QOL.

Conclusion and Recommendations: SLE patients can benefit from different coping strategies to better deal with their health condition and improve their QOL. Health care providers should be aware of healthy coping strategies skills to help patients strengthen the use of strategies that improve their QOL. Further research using a larger sample, including both genders and qualitative research strategy are recommended.

Keywords: Quality of Life, Coping Strategies, Systemic Lupus Erythematosus.

1. INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune and life-threatening disease that is common among young females aged 15 to 45 years. The disease characterized by a relapsing and remitting sequence that affects patients' quality of life (QOL)(Pons-Estel, 2010). Like any chronic disease SLE has physical, psychological, social and financial effects on the patients and their families (Ward, Schiller, & Goodman, 2014). Patients with SLE experience physical symptoms as pain, fatigue, joint pain, muscle aches, sleep disorders plus the side effects of the therapy (Sperry, (2011),

psychological disorders such as anxiety, depression, and mood swing in addition to social isolation that affect the patients' overall QOL (Faria, et al 2015; Cordoba-Slnchez, 2015). As many chronic illnesses and with the persistence and remission of the symptoms, patients might experience hopelessness, and helplessness (Beckerman, Auerbach, & Blanco, 2011).

Dealing with such condition is difficult and requires a great deal of coping and adjustment. SLE patients need to learn how to cope with their chronic condition to be able to manage their disease efficiently. Evidence has postulated that coping play an important role in improving the health-related quality of life in patients with chronic disease including SLE (Waldron et al., 2011). Coping portrays a set of planned strategies that an individual can do to reduce physical, psychological or social harm and improve the QOL. In addition, studies have explored that coping enhance patients' ability to practice fair physical life, improve psychological wellbeing and show more involvement in the social life regardless the state of disease (Bricou et al., 2006; Rinaldi, 2006). The aim of this study was to examine the effect of educating SLE patients about different coping strategies to improve their QOL.

2. METHODS

Design: A quasi excremental pre and post-test design was used to achieve the aim of the study. **Sample and setting:** A convenience sample of 40 patients with SLE were included in the present study. Patients were approached during the first awareness campaign for SLE held by the Saudi Association of Rheumatic Disease, 2015, Riyadh City, KSA. Patients were interviewed by the researches in a structured interview.

Tools of the study: Socio-demographic characteristics of the patient as; age, marital status, occupation, education, working and familial history of the disease. A revised version of Coping Strategy Questionnaire (CSQ) (Rosenstein & Keefe, 1983). This tool is used to assess patients' self rating of cognitive and behavioral strategies to cope with pain. The questionnaire has four subscales (Catastrophizing, Diversion, Reinterpreting, and Cognitive Coping) with a total of 23 items. The tool is 5 points Likert scale with (5) always, (4) often, (3) sometimes, (2) rare and (1) never. The score ranges from 23 to 115, with higher scores indicating frequent use of coping strategies to control and cope with pain. In addition, SLE QOL questionnaire (Leong et al., 2005) was also used to assess patients' QOL. The questionnaire is 40 items with 6 subscales including physical activities, social/occupational activities, symptoms, medical treatment, emotions/mood and feelings. The questionnaire is 7 points Likert scale with a score that ranges from 40 to 280, where the higher indicates worse QOL. Both CSQ and SLE QOL questionnaires have been used extensively and have good reliability. Reliability of the questionnaires was tested and reported as Cronbach's alpha of .85 for CSQ and .87 for the SLE QOL questionnaire.

Procedure of data collection and ethical considerations: One of the researchers has her sister diagnosed with SLE and join a social group (40) who are having the disease and communicate through chatting in the group. The idea of the study and the purpose were explained to the group through chatting and arrangement to meet and conduct the study was done. All patients were approached during the first awareness campaign for SLE held by the Saudi Association of Rheumatic Disease. Before the start of the awareness campaign, the researchers approached the patients, the study objectives were explained in detail and for those who agree to participate a consent was taken and initial data on QOL was assessed. The awareness campaign included information about the disease, signs and symptoms, possible treatment and available resources for the patients. The researchers participated in the campaign by conducting the educational session about different coping strategies for SLE patients. Three to four weeks later, data on the used coping strategies and QOL were collected through a structured interview after arrangement with the participants. Confidentiality was secured by using numbers instead of names and the communication for meetings for data collection were through chatting on the social group. Participants were also told that the obtained data will be used only for the research objectives.

3. RESULTS

Table 1 showed that majority (92.5%) were young females with a mean age of 29.6 (10.1). More than half 52.5% were married and 40 % were singles. Regarding educational level, 52.5% had elementary school degree, 37% were high school graduates and 5% were either university graduates or having master's degree. Forty percent were not working, out of them 22.5% were working administrative work and 17.5% professional work. The 60% who were not working were studying. Majority of the participants (82.5%) reported having no family history of SLE.

Table 1 Demographic characteristic of the study sample

Characteristics	(n=40)	
	N	%
Mean age (in years)	29.6(10.1)	
Gender		
▪ Female	37	92.5
▪ Male	3	7.5
Marital Status		
▪ Married	21	52.5
▪ Single	16	40
▪ Divorced	2	5
▪ Widowed	1	2.5
Education		
▪ Elementary	21	52.5
▪ High school	15	37.5
▪ University graduates	2	5
▪ Postgraduate (master)	2	5
Working Status		
▪ Working	16	40
▪ Not working	24	60
Type of Work		
▪ Studying	24	60
▪ Administrative	9	22.5
▪ Professional	7	17.5
Family History of SLE		
▪ No	33	82.5
▪ Yes	7	17.5

Table 2 presents participants' QOL before conducting the coping strategies educational session. Results illustrated that 61% of the patient reported that physical activities not troubled at all. Half of them reported that emotions/mood and feelings not trouble at all. Social/occupational activities, symptoms and medical treatment reported as not troubled at all among 47% and 46% of participants respectively.

Table 2 Percentage of QOL sub scales among patients with SLE before conducting coping strategies educational session

QOL Items	Not troubled at all	Hardly troubled	Somewhat troubled	Moderately troubled	Quite troubled	Very troubled	Extremely troubled
Physical activities	61%	12%	12%	6%	4%	5%	0%
Social/occupational activities	47%	15%	12%	10%	6%	9%	1%
Symptoms	46%	14%	10%	17%	3%	6%	4%
Medical treatment	46%	11%	13%	12%	5%	6%	7%
Emotions/mood	50%	16%	10%	5%	5%	7%	7%
Feelings	51%	13%	12%	9%	5%	4%	6%

As presented in Table 3, results of the participants' coping strategy showed that for catastrophizing coping strategies, 57.5% never feel like they can't go on, 42.5% rarely felt that they can't stand it anymore, 50% never feel that it is awful, and it overwhelms them.

Regarding diversion coping strategy; majority (82.5%) indicated that they always think of people they enjoy doing things with and they think of things they enjoy doing. More than two thirds said that they always do anything to get their mind off the pain and that they do something they enjoy. In addition, 52.5% always replay in their mind pleasant experiences in the past.

As for reinterpreting coping strategy, 52.5% indicated that they always and 25% often pretend that pain is not part of them, 40% always and 30% often pretend that pain is not there. 27.5% always and 42.5% often try to feel distance from the pain. In addition, 22.5% always and 42.5% often imagine that the pain is outside their bodies, 25% always and 37.5% often try to think of pain as something separate from them.

In relation to cognitive coping strategy, more than half of participants specified that they always see it as a challenge and did not let it bother them, no matter how bad pain gets, they know they can handle it and although it hurts, they just keep on going.

Table 3: Distribution of number and percentages of coping strategies among patients with SLE after the educational session

	Always	Often	Sometimes	Rare	Never
Catastrophizing					
It is terrible, and I feel it is never going to get any better.	2(5)	0 (0)	6(15)	22(55)	10(25)
It is awful, and I feel it overwhelms me.	1(2.5)	3(7.5)	4(10)	12(30)	20(50)
I worry all the time about whether it will end.	5(12.5)	7(17.5)	11(27.5)	7(17.5)	10(25)
I feel my life isn't worth living.	0(0)	0(0)	0(0)	0(0)	0(0)
I feel like I can't go on.	2 (5)	5(12.5)	9(22.5)	1(2.5)	23(57.5)
I feel I can't stand it anymore.	0(0)	2(5)	4(10)	17 (42.5)	17(42.5)
Diversion					
I try to think of something pleasant.	19(47.5)	20(50)	1(2.5)	0(0)	0(0)
I replay in my mind pleasant experiences in the past.	21(52.5)	9(22.5)	6(15)	4(10)	0(0)
I think of people I enjoy doing things with.	33(82.5)	6(15)	1(2.5)	0(0)	0(0)
I think of things I enjoy doing	33(82.5)	5(12.5)	1(2.5)	1(2.5)	0(0)
I do anything to get my mind off the pain.	25(62.5)	10(25)	5(12.5)	0(0)	0(0)
I do something I enjoy, such as watching television or listening to music (Quran)	27(67.5)	13(32.5)	0(0)	0(0)	0(0)
Reinterpreting					
I try to feel distant from the pain, almost as if the pain was in somebody else's body.	11(27.5)	17 (42.5)	9(22.5)	3(7.5)	0(0)
I try not to think of it as my body, but rather as something separate from me.	10(25)	15(37.5)	8(20)	4(10)	3(7.5)
I imagine the pain is outside my body.	9(22.5)	17(42.5)	10(25)	2(5)	2(5)
I pretend it's not part of me.	21(52.5)	10(25)	1(2.5)	9(22.5)	0(0)
I pretend it's not there.	16(40)	12(30)	4(10)	4(10)	4(10)
Cognitive Coping					
I tell myself I can't let the pain stand in the way of what I have to do.	19(47.5)	9(22.5)	5(12.5)	5(12.5)	2(5)
No matter how bad it gets, I know I can handle it.	21(52.5)	9(22.5)	3(7.5)	4(10)	3(7.5)
I see it as a challenge and don't let it bother me	23(57.5)	10 (25)	0(0)	7(17.5)	0(0)
Although it hurts, I just keep on going.	21(52.5)	9(22.5)	3(7.5)	4(10)	3(7.5)
I just go on as if nothing happened.	16(40)	12(30)	4(10)	4(10)	4(10)

To better present the utilized coping strategies among participants, total percentage of the coping strategies was calculated, and results showed in table 4. Diversion coping strategy was the most frequently used (80% always and 10% sometimes), followed by cognitive coping strategy (65% always, 25% often) and then reinterpreting coping strategy (45% always, 35% often and 17.5% sometimes). Further, catastrophizing was the least used coping strategy (37.5% never, 25% rare, 20% always, and 10% sometimes).

Table 4: Total frequency of used coping strategies among patients with SLE

Items	Always		Often		Sometimes		Rare		Never	
	#	%	#	%	#	%	#	%	#	%
Catastrophizing	8	20%	3	7.5%	4	10%	10	25%	15	37.5%
Diversion	32	80%	1	2.5%	4	10%	2	5%	1	2.5%
Reinterpreting	18	45%	14	35%	7	17.5%	0	0%	1	2.5%
Cognitive	26	65%	10	25%	2	5%	1	2.5%	1	2.5%

QOL was also measured after conducting the coping strategies educational session. As illustrated in Table 5, comparison between QOL before and after the coping strategies educational session showed that, regarding physical activity, 56% reported good, 16% fair and 28% poor QOL pre, while 73% reported good, 22% fair and 5% poor after the educational session.

Social/occupational activities, reported as good among 43% good, 23% fair and poor among 34% pre the session, while reported as 62% good, 28% fair and 10% poor respectively post the educational session.

Good symptoms QOL presented among 40% pre and 60% post, fair among 28% pre and 25% post, and poor among 32% pre and 15% post the educational session.

Medical treatment and Feelings coping strategies pre the educational session reported as good among one third and reached up to two thirds after the educational session. Emotions on the other hand showed improvement as it was good among 56% pre and 66% post, fair among 11% pre and 20% post while poor among 33% pre and 14% post.

Table 5: Comparison of QOL pre and post the coping strategy educational session among SLE patients

QOL Subscales	Good		Fair		Poor	
	Pre	Post	Pre	Post	Pre	Post
Physical activity	56%	73%	16%	22%	28%	5%
Social/Occupational activities	43%	62%	23%	28%	34%	10%
Symptoms	40%	60%	28%	25%	32%	15%
Medical Treatment	32%	57%	25%	30%	43%	13%
Emotions/Mood	56%	66%	11%	20%	33%	14%
Feelings	37%	64%	22%	26%	41%	10%

To examine if there were a relationship between coping strategies and QOL among patients with SLE, Pearson Product Moment Correlation analysis was conducted and results showed that there was a statistically significant correlation between coping strategy diversion and physical activity QOL ($r = .40^{**}$, $p = .01$), social/occupational activity ($r = .34^*$, $p = .02$), symptoms ($r = .31^*$, $p = .01$), emotions/mood ($r = .40^{**}$, $p = .03$) and feelings ($r = .34^*$, $p = .001$) indicating that patients who used diversion coping strategy were more likely to have a good physical, social/occupational, symptoms, medical treatment and feelings QOL.

Reinterpreting coping strategy reported statistically significant correlation with social/occupational ($r = .29^*$, $p = .001$), emotions/mood ($r = .35^*$, $p = .004$), feelings ($r = .31^*$, $p = .001$) meaning that patients who used reinterpreting coping strategy were more likely to have good social/occupational, emotions/mood and feelings QOL.

Cognitive coping strategy reported statistically significant correlation with social/occupational activity ($r = .34^*$, $p = .01$) and feelings ($r = .28^*$, $p = .01$) demonstrating that when patients use cognitive coping strategy, they have good social/occupation activities and better feelings QOL. Results of correlations between coping and QOL are presented in table 6.

Table 6: Correlation between coping strategies and QOL among patients with SLE

Coping Strategy	QOL					
	Physical Activity	Social/occupational activities	Symptoms	Medical treatment	Emotions/Mood	Feelings
Diversion	r = -.40** p = .01	r = -.34* p = 0.02	r = -.31* p = 0.01	r = -.031 p = 0.32	r = -.40** p = 0.03	r = -.34* p = 0.001
Reinterpreting	r = .02 p = 0.31	r = 0.29* p = 0.001	r = 0.10 p = 0.27	r = .001 p = 0.31	r = .35* p = 0.004	r = 0.31* p = 0.003
Cognitive coping	r = -.010 p = 0.33	r = -.34* p = 0.01	r = -.01 p = 0.25	r = .003 p = 0.45	r = 0.04 p = 0.71	r = 0.28* p = 0.01

4. DISCUSSION

SLE is a common disease even among young females and its clinical manifestations are hard to predict like many chronic diseases. The aim of the present study was to examine the effect of educational session of coping on the QOL for patients diagnosed with SEL. Result of the present study showed that majority of participants were young females, and this was consistence with previous works who indicated that SLE is common among females in young ages (Fing et al., 2010; Budhoo, et al. 2017).

Results from the current study showed relatively low QOL before conducting the coping strategy educational session. Previous results reported similar findings that QOL of patients with SLE is affected in various dimensions as well as their satisfaction with life (Kulczycka, el al 2010; Kozora et al., 2005; Jolly et al 2014).

As evidenced by Kozora et al., (2005), cognitive behavioral intervention aimed to change maladaptive cognitions and behaviors can be very effective for patients with SLE. Using diversion, cognitive and reinterpretation coping strategies was frequent among participants in this study and showed significant association with QOL. As Muslim, faith in God support would have enhanced participants ability to accept their disease and reinterpret their pain as a test from God that they would tolerate to receive rewards from God. This was supported by Rinaldi et al. (2006) who found that patients with SLE are more likely to use strategies such as acceptance of the situation and turning to religion. A considerable percentage of participants in this study also used cognitive coping more frequently. This would have helped them to well reinterpret their pain and cope with their health condition. Although, 10% of participants in this study had university and master’s degree, and majority had elementary and high school, but majority were able to get benefit from the educational session on coping strategy to choose effective coping. This also reflected in that 60% of participants in this study were utilizing their time studying higher degree instead of giving up. Neville et al. (2014) in their study concluded that both SLE patients and healthcare professionals acknowledged the need for information regarding coping and resources to enhance patients’ engagement in health care and self-management. In addition, previous research postulated that using a cognitive behavioral treatment attained a significant decrease in the level of depression, anxiety and daily stress, along with a significant improvement in health related QOL and symptoms among SLE patients (Navarrete et al., 2010, Haupt, et al., 2015).

The educational session about coping strategy in this study was effective. Patients were able to use the more effective coping strategies such as diversion, reinterpreting and cognitive strategies and they were less likely to use catastrophizing coping strategy. Previous research concluded that maladaptive coping characterized by catastrophizing is associated with increased pain experience (Somers 2012; Sullivan 2001).

Limitations:

Although, the educational session on coping was effective in improving the QOL among SLE who participated in the current study, there were some limitations. The small proportion of male patients in this study rendered detecting gender differences in coping strategies. Relatively small sample size would limit generalization of results. The current study did not look at presence of comorbidities that would potentiate association with QOL among SLE patients.

5. CONCLUSION AND RECOMMENDATIONS:

SLE patients can benefit from different coping strategies to better deal with their health condition and improve their QOL. Health care providers should be aware of healthy coping strategies skills to help patients strengthen the use of strategies that improve their QOL. Further research using a larger sample, including both gender and qualitative research strategy are recommended.

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