# Social Support and Stress Symptoms of Lupus Patients

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The effects of social support on reducing the stress symptom of lupus patient were shown by Nugraha (2005). This article was intended to describe the social support used during the social support activities. In this study social support was given to two lupus patients during 12 weeks (once a week, two hours max. every session), applying the one-to-one method and helping techniques from Brammer (2003). The results described that support techniques mostly used to fulfil the patients' needs for emotional and informational supports were attending, reassuring, and summarizing; whereas the supports mostly used were the roles as a friend who listened to the patient, who encouraged them and who gave them information related to lupus. The descriptions also revealed that the author needed several sessions to show that social support affects the patients.

Keywords: social support, stress, lupus patient

Penelitian Nugraha (2005) memperlihatkan bahwa pemberian dukungan sosial mengurangi keluhan simptom stres penderita lupus. Artikel ini bermaksud menggambarkan dukungan sosial dalam aktivitas pemberian dukungan sosial tersebut. Pada studi ini dukungan sosial diberikan terhadap dua penderita lupus selama 12 minggu (satu kali seminggu, dua jam maksimum pada tiap pertemuan), menggunakan metode *one-to-one support* dan teknik *helping* menurut Brammer (2003). Hasilnya menggambarkan bahwa dalam rangka memenuhi kebutuhan penderita lupus akan dukungan emosional dan dukungan informasional, tiga teknik yang sering digunakan oleh peneliti adalah *attending*, *reassuring*, *summarizing*; sedangkan peran yang sering dimainkan peneliti adalah peran sebagai teman yang mendengarkan, teman pemberi semangat, dan teman pemberi informasi. Deskripsi juga mengungkapkan bahwa efek dukungan sosial terhadap penderita lupus baru tampak setelah beberapa pertemuan berlangsung.

Kata kunci: dukungan sosial, stres, penderita lupus

'Lupus', which is the Latin word for 'wolf', refers to a disease characterized by butterfly-shaped rashes found in the patients' facial features, which gives the patients wolf-like facial appearances. The terminology *Lupus Erythematosus* itself was proposed for the first time by Pierre Cazenave, a French dermatologist, back in 1851.

Lupus Erythemathosus, commonly called"lupus", is a chronic disease categorized as autoimmune disease (disease which is caused by maladaptive autoimmune system of the human body). The autoimmune system attacks internal organs, healthy bodily cells, and causes damage and dysfunction to the patient's body. Lupus is also classified as a multisystem disease because it attacks different internal organs or cell networks. Lupus

is characterized by a remission period (a period of dormant state) and relapse period (or commonly called 'flare', that is the active state of the disease). Based on its overt symptoms, *Lupus Erythematosus* can be classified into four groups, namely *Discoid Lupus Erythematosus* (DLE), *Systemic Lupus Erythematosus* (SLE), *Drug-Induced Lupus Erythematosus*, and *Undifferentiated Connective Tissue Disease* (UCTD). In this article, the author specifically refers to *Systemic Lupus Erythematosus* (SLE).

Commonly associated symptoms of Lupus are the appearance of butterfly-shaped red rashes found at the patients' cheeks and noses, chronic fatigue, decreasing of body mass, skin rashes, chronic infection, anemia, fever, arthritis, hair loss, chronic oral ulcer, muscular and joint pains, which paralyze upper and lower extremities. These symptoms are similar to influenza, hence it is often called *flulike syndrome*. Because of this flulike symptoms, lupus is often called 'great imitator'. The

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difficulty of discerning Lupus from common influenza often frustrated doctors and patients alike, because—unlike the real influenza—the flulike symptoms of Lupus showed no sign of diminishing. Usually, only after a Lupus patient had visited many doctors that proper diagnostic was finally made.

Lupus Diagnostic Criterion was first formulated by The American College of Rheumatology (ACR) in 1971. The criterion was revised in 1982 and 1996. There are 11 criterion under three axis, namely A (skin-related criterion), B (organ-specific related criterion), and C (laboratory related criterion). Axis A consists of (1) butterfly rash (butterfly-shaped lupus rashes appeared on cheeks and noses), (2) discoid rash (circular shaped rash appeared on body parts exposed to sunlight), (3) sensitivity to sunlight (rashes that appeared after exposure to sunlight), (4) oral ulcer (ulcers found in the mouth or nose). Axis B consists of (5) arthritis (inflammatory around joints), (6) serositis (inflammatory in pleura or pericardium region), (7) renal disturbance (the existence of protein found in urine and abnormal sediments, which can be seen under microscope), and (8) neural disturbance. Axis C consists of (9) blood anomalies (hemolytic anemia, lower leucocytes), (10) immunity disturbance (blood tests revealed antiphospholoid antibody, anti-coagulant lupus, anti-DNA, false-positive syphilis test or positive Anti-Sm), and (11) ANA-test positive. These criterion have been used in the diagnostic of Systemic Lupus Erythematosus. However, the same criterion saw no use in the diagnostic of Drug Induced Lupus or Discoid Lupus. The emergence of four (from eleven) criterion already confirm the presence of lupus.

There are various factors associated with the etiology of lupus, such as (1) genetic factors, especially the capability to generate autoantibody class-II Human Leukocyte Antigen, (2) environmental factors, such as ultraviolet rays, a number of drugs and chemical ingredients which may induce lupus, (3) abnormality factors within bodily immunity system, such as abnormality of lymphocyte B and T, the alteration of cell warning system, abnormality of immunoglobulin response, apoptosis, and the decreasing of immunity response.

A number of characteristics usually found in lupus patients are: (1) age: although lupus has been found at newly born babies and patients above 89 years old, about 80% lupus patients were 15-45 years old of age, (2) gender: nearly 90% lupus patients aged 15-45 years old are female, (3) nationality and geography: Afro-American, Latino, and Asian possess greater risk at getting contracted Lupus, compared to Caucasian.

In reality, lupus is not a fatal disease, although present

medical treatment has not yet been able to cure lupus. Mostly, medical treatment was aimed at reaching remission phase, which was characterized by the disappearance of symptoms. Doctors usually advise the patients to avoid either physical or psychological stress, because both stresses may enlarge the probability of incoming"flare". To acquire remission period, patients need to undergo a change of lifestyle, emotional regulation, proper drugs usage, and balanced nutritional intake. The rationale is the fact that lupus may affect work, family, sexual, financial, and other aspects of individual life.

Based on interview of 10 lupus patients in Bandung, it was found that change of lifestyle is a necessary requirement for the patients, due to a number of reasons (Nugraha, 2004), namely: 1) the requirement of medical treatment procedures to control various symptoms of the disease, 2) prevention action so that any routine activities do not worsen the disease, 3) the presence of physical pain or other symptoms that hamper the patients' capability during work, school, play, or interpersonal relationship. These reasons often cause the lupus patients to quit working or restrict their daily activities. For example, patients who were previously connected with considerable outdoor activities must now stay at home. Subsequently, household roles would undergo changes. Independent individuals must undergo changes into more dependent individuals. However, the patients' families often restricted or prohibited the patients from doing their routine activities that they were used to do prior to the disease. Although this prohibition might be done out of goodwill, this often worsened the patients' feeling of helplessness. The patients who formerly used to have a professional work often denied their illness; they forced themselves to go to work, out of their fear for being labeled as unproductive. Interviews also revealed negative affects experienced by the patients, similar to those experienced by other chronic disease patients. According to the patients' disclosure, oft-experienced feelings were helplessness, pessimistic, anger, agitation, uncomfortable, fear of death, sadness. At least seven participants experienced these feelings (see Nugraha, 2004).

Due to the immense and wide impact of lupus toward the patients' lives, according to Dalton (2001), lupus has very high potential to become stressor for the patients (see also Noellen-Hoeksema, 2001). The presence of negative emotions, as disclosed by lupus patients, revealed this potential for becoming stressors (see Taylor, 2003; Sarafino, 1994). Stress that was experienced by lupus patients would worsen the disease itself. Ironically, stabile and calm psychological states

are very much required by lupus patients in order to diminish the probability of incoming 'flares'. During these times of crisis, social support is a necessity (see Greenberg, 1980; Wallace, 2000; Phillips, 2001, Glanz, 2002).

Information obtained from interviews with lupus patients revealed that family support often helped the patients to perform their functions and roles at home. There were various forms of family supports, but the most prominent were support in doing daily chores, and material support. Usually, the patients felt that family support really helped them. These patients reported less anxiety and experienced the relieving of their psychological burdens. Social support can also be obtained from individuals outside the family, for example from friends (either non-lupus friends or friends who contracted similar disease, see Nugraha, 2005).

Syamsi Dhuha Foundation is an organization which assembled individuals who gave support to lupus patients. Founded in 2003, this foundation has more than 100 members. There were several actions already taken by Syamsi Dhuha Foundation in order to help lupus patients (called 'Odapus' or 'Orang dengan Lupus', meaning 'people who contracted lupus'), such as (1) action to provide emotional support in the form of home/hospital visit, (2) action to provide informational support, such as educating the patients (or their families) regarding the nature of Lupus and the visual damage which often accompany Lupus (Care for Low Vision); action to help and facilitate personal capability development by means of training or mutual share of experience (Majelis Ilmu Riyadhus Sakinah); action to assist the patients in changing their attitudes toward various life problems by means of religious approach (using spiritual healing and mutual sharing between lupus patients and health volunteers), (3) action to provide instrumental support (such as financial support for the impoverished lupus patients or utility support—such as a wellchair—for disabled patients).

Although Syamsi Dhuha Foundation has accomodated a number of routine events for their members (so that the members may share and swap experiences to each other), rarely did the members attend to the events. Partly this was because the patients' physical conditions restricted them for attending the regular events. In other cases, sometimes the patients were living too far from the Foundation that they could not been able to attend the events. These circumstances might explain why any *available* support had not been perceived as *real* support by lupus patients. Nugraha's

(2005) report revealed that among the four types of supports needed by lupus patients (emotional, instrumental, informational, and companionship support), two of the most often unfulfilled supports were emotional and informational support. This circumstance indicated that lupus patients who were involved as research participants felt that they do not have any person to whom they can disclose themselves with; who are willing to listen them sympathetically, giving sincere attention, and unconditionally accepting them. The lupus patients also perceived the lack of information related to lupus, and the emotional problemsolving which was sorely needed after the emergence of the symptoms of the disease. This information will help the patients to maintain a more positive evaluation of his or her illness, which in turn will lessen the symptoms of stress.

As a theoretical construct, social support has been defined as the degree of how an individual merges into his or her social environment, reveals sense of ownership, obligation, and intimacy. Social integration, on the other side, has been defined in terms of social structure and quantity of relationship (such as the size and density of social network, the frequency of interaction). Social support has been defined as the function and quality of social relationship (such as perception toward available assistance or perception toward support given by others). Social support occurs through interactive process, and can be related with altruism, sense of obligation, and perception toward reciprocity (Schwarzer & Leppin, 1991, in Schwarzer & Knoll, 2007).

Schwarzer, Knoll & Rieckman (2004, in Schwarzer & Knoll, 2007) proposes various ways to define social support, namely: (1) social support that can be seen as resources given by others. In this sense, support can be instrumental or tangible (such as donating objects), informational (giving advice), and emotional (listening empathically). Resources can be given to assist coping process, as a mean of trading with other resources, or can be defined as personality traits. (2) Social support can be seen as discrepancy between available support and actual support received. Both of these constructs may have strong relationship or no relationship at all, depends on the context of the study (Schwarzer, Dunkel-Schetter & Kemeny, 1994a, in Schwarzer & Knoll, 2007). However, the measurement of both constructs revealed similarity among the two constructs. Both measurements quantify social interaction within specific timeframe, by means of self-report technique. (3) Social support can also be defined as discrepancy between perception of available support and the actual support received by individual. The difference is that perception toward available support refers to anticipation toward the given assistance, hence it is always be prospective in nature, either implicit or explicit. Meanwhile, the actual support received refers to available assistance within certain timeframe, hence it is always be restropective in nature.

Social support plays important role during stress and coping. According to transactional stress theory (Lazarus & Folkman, 1984, in Schwarzer & Knoll, 2007), support is one type of resource that affects cognitive appraisal of individuals who experience stress. In this sense, coping is a product of cognitive appraisal. The more support received by the patients, the better the coping that will be facilitated. Resources affect coping, and coping provides various adaptational outputs. This three-step approach has been confirmed by several studies. The study conducted by Holahan, Moos, Brennan (1997, in Schwarzer & Knoll, 2007) which explored social adaptation of cardiac patients, revealed that patients who perceived themselves as getting support, tended to choose active coping strategy and tended to be more approach-oriented. This dynamic, in turn, would lessen the symptoms of depression. Luszcybska, Mohamed, & Schwarzer (2005, in Schwarzer & Knoll, 2007) found that support and self efficacy could serve as resources of support for cancer patients who undergone operations. Boehmer, Luszczynska, Schwarzer in Schwarzer & Knoll, (2007), summarized that support and self efficacy might predict active coping, which in turn increased the wellbeing of tumor patients.

Social support may affect stress and coping via its interaction with individual's stressful experience. The effect of social support toward stress has been known as *stress-buffering effect*. This effect is based on postulate that stated that social support can provide beneficial effects toward individual's health and emotion during stressful situations, because social support dampens negative affects experienced by the person. (Schwarzer & Leppin, 1991, in Schwarzer & Knoll, 2007). Those mediating effects have been proposed in several hypotheses, such as:

1. The enabling hypothesis: social support enables self-efficacy.

According to proactive agentic point of view from Benight and Bandura (2004, in Schwarzer and Knoll (2007), support providers may facilitate an individual's self regulation by enabling one's adaptive capabilities to face challenges and to overcome adversity. In this understanding, support is not seen as just a potential proactive cushion against environmental demands. This facilitation may work in three possibilities, i.e.

(1) social support may provide an opportunity to engage in vicarious experiences in dealing with a stressor at hand. It is particularly true when support is received by persons who have to deal with the same stressor and demonstrate competency in doing so, (2) social support may represent a symbolic experience in which members of the network provide verbal assurance of the support recipient's competency to deal with the problem, (3) social support may reduce stress-related arousal, so it provides another source of increased self-efficacy. In this way, stress-related arousal and negative affect may be used as a source of information concerning one's own competence to cope with a situation at hand.

2. The cultivation hypothesis: self efficacy maintains and cultivates social support.

Self-efficacy operates as an establisher of support that could be accomplished by self-regulatory social activities. For example, people take the initiative to go out and make social contacts, or they take actions to maintain valuable social relationships, and they invest effort to improve, extend and cultivate their networks. In this manner, their supportive resources will be improved along with their increasing self-efficacy.

3. Support and coping: provided support facilitates coping

Social support theories are intertwined with the concepts of stress and coping. The cognitive appraisal of stress depends partly on the perceived availability of social resources. Coping is also supposed to depend on such resources. Based on the studies on cancer surgery patients by Schulz and Schwarzer (2004, in Schwarzer and Knoll (2007), the researchers concludeed that coping could generate more or less support, and that support could facilitate coping.

This article presents the study of social support received by lupus patients, or sometimes called Odapus ("orang dengan penyakit lupus"—people with lupus). Starting from exploration of experience of lupus patients who were listed as members of Syamsi Dhuha Foundation, Nugraha (2005) identified discrepancy between need for support and perceived support, especially related to emotional support and informational support. Based on this preliminary finding, Nugraha designed an intervention program that provides social support for lupus patients. This particular intervention program was subsequently applied as a research project, in which Nugraha compared lupus patients who received social support (particulary emotional and informational support) and lupus patients who received none of those supports. The research was conducted toward lupus patients who have been listed as members

of Syamsi Dhuha Foundation. Results revealed that social support might lessen stress symptoms experienced by lupus patients. However, the report mentioned no reference of the particular type of the given social support. This article, therefore, attempts to describe the type of social support given to the lupus patients at Syamsi Dhuha Foundation.

#### Method

# Social Support as an Intervention Technique

As a form of intervention technique, social support was designed according to intervention design as proposed by Cohen, Underwood, and Gottlieb (2001). This design consisted of a number of aspects, namely aim, method, reachability, target, duration, and location.

### Aim of Social support

The aim of social support is to provide emotional and informational support toward research participants, so that they may build better resources which enable them to give a more positive evaluation toward their illness. Specifically, it was hoped that after the provision of social support, the research participants may: (1) Obtain the knowledge that they have friends to whom they can disclose themselves with; friends who will support them, console them during grievous times, and who will accept them unconditionally. (2) Obtain information about ways to handle problems efficiently. (3) Be able to give a more positive evaluation toward the problems they have been experiencing.

# **Method of Social Support Provision**

In this study, social support has been provided as one to one support, which is a type of individual support which was given directly to intervention targets (in this sense, the research participants). This social support, which offered a new supportive relationship, might serve to overcome the lack of social support experienced by participants (due to their physical disability which restricted them to seek support from their social environment).

#### **Reachability of Social Support**

According to needs assessment conducted prior tothis study, reachability of social support given in this research encompasses: (1) emotional support in the

form of friends to whom the participants can share with and who accept them unconditionally, and (2) informational support in the form of information, advice, or knowledge needed by participants during times of crisis.

# **Social Support Provision Technique**

Support was given using helping technique underlined by Brammer (2003), which consisted of two stages. At the first stage, the author focused on building relationship, meanwhile at the second stage, the author focused on facilitating positive action. During the first stage, intervention activity was aimed at building a supportive relationship, which might be perceived by intervention targets (research participants) as a form of support. During the second stage, intervention activity was aimed at helping participants solving their problems. Provision of informational support was aimed at helping intervention targets in seeking alternative solutions and creating action plan which eventually leads toward problem solving.

The stage of building relationship consists of (1) preparing research participants for the upcoming events and building rapport with the participants (this stage is also called entry stage), (2) seeking clarification of the problems that the participants are experiencing, (3) formulate contract and structure of the upcoming meetings (this stage is called structure stage), (4) developing beneficial relationship between support givers and support receivers.

The stage of facilitating positive action consists of (1) exploring the problems and gathering facts, setting goals, planning strategies, (2) seeking alternatives, understanding feelings, practice or consolidate new skills, (3) designing action plan for problem solving, diminishing negative feelings, (4) evaluating results and terminating relationship.

During the latter stages, the techniques used in this study were modeled after techniques used in the helping process. In order to provide emotional support, the author applied specific techniques related to listening (namely attending, paraphrasing, clarifying and perception checking) and supporting (namely contacting, reassuring and relaxing). In order to provide informational support, the author applied informing techniques (namely giving information, giving advice, and suggesting).

#### **Social Support Intervention Targets**

Intervention targets (who received social support) are research participants. This study was conducted at two lupus patients who contracted *systemic lupus* 

erythematosus, which has been enlisted as members of Syamsi Dhuha Foundation for minimum two years. In order to be able to be included as participants, the patients must be active participants of the Foundation's events, must be in remission stage, and possessing similar educational degree. The patients must have contracted lupus for less than three years, because it was assumed that such patients possess higher degree of stress compared to patients who have been contracted lupus for more than three years. During these times of stress, supports are much needed.

# **Observation and Monitoring**

During every session, activities were recorded on activity sheets in order to examine whether support has been given according to schedule. These sheets consist of records related to date and time of each session, the topic discussed during the session, the techniques and supports given during each session, and the reactions of research participants.

# **Duration and Location of Support**

Social support activity was conducted once a week for 12 (twelve) weeks. The rationale is that the aforementioned timeframe allows the building of supporting relationship and the possibility of permanent changes. Social support activity was conducted at the home of support receivers (research participants) because it was hoped that support might be given in an unstructured, informal activity (Cohen, Gottlieb & Underwood, 2001). Each session lasted for about two hours.

#### **Instrument of Measure**

The instrument used in this study was an adaptation of *Berlin Social Support* (Ralf Schwarzer, 2002). It was a self-report that measures *perceived support*, *need for support* and *received support*. The substance of this instrument was developed after four support functions mentioned by Cohen, Underwood and Gottlieb (2001), namely *emotional support*, *informational support*, *instrumental support*, and *companionship support*.

# Procedure of Giving Social Support as Intervention Technique

As a review, it must be noted that the activity conducted in this study belonged to the final stage (third stage) from the battery of procedures for providing social supports as follows: (1) Measurement of social

support to gain perspectives needed by the participants. (2) Action plan to provide social support needed by the participants. (3) Providing social support required by the participants, according to the prescheduled plan.

#### Data

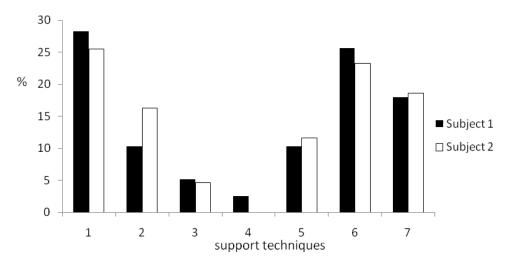
Data resources in this study were activities of social support (specifically, emotional and informational support) provided by the author of this study, for research participants, within 12 sessions. These activities were recorded in activity sheets filled by the author during every social support session. The sheets contain records of date, time, topic, technique used in the session, support given, and reaction of research participants. As has been previously mentioned, social support was given in the form of one-to-one support, utilizing helping technique proposed by Brammer (2003).

### **Data analysis**

The activity sheets filled by participants during each social support session were subsequently coded in order to identify social support techniques given to participants. Coding was conducted by three researchers, namely the author of this study and two fellow psychologists. Coding was conducted individually and then followed by discussion among the three researchers in order to summarize the findings obtained from the coding processes. Finally, measurement of percentages was conducted. During the measurement of social support technique, each social support technique was divided by the total amount of social support techniques, then multiplied by 100%. Similar measurement approach was taken for the measurement of social support. Results are shown as graphical forms, below.

## **Results and Discussion**

This section focuses on describing research results, specifically related to the dynamics of social support given to lupus patient. Results are shown in graphical and table forms, followed by discussion: (1) Social support technique used as intervention toward subject 1 and subject 2 (Figure 1); (2) Support given as intervention toward subject 1 and subject 2 (Figure 2); (3) Excerpts from interview and observation results of subject 1 (see Table 1 on Appendix A); (4) Excerpts from interview and observation results of subject 2 (see Table 2 on Appendix B).



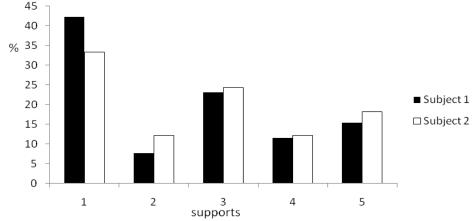
Note. 1. Attending, 2. Paraphrasing, 3. Clarifying, 4. Perception checking, 5. Giving Information, 6. Reassuring, 7. Summarizing

Figure 1. Social support technique used as intervention of subject 1 and subject 2

Overall, results showed that the three most-applied social support techniques were *attending* (subject 1, 28.21%; subject 2, 25.58%), *reassuring* (subject 1, 25.64%; subject 2, 23.26%), and *summarizing* (subject 1, 17.95%; subject 2, 18.60%). Social support techniques that saw no use at all were *giving advice*, *suggesting*, *contacting*, *and relaxing*. Although the other four techniques (*paraphrasing*, *clarifying*, *perception checking*, *giving information*) were put to use, however their amount of usage were not as often as the previously mentioned three techniques. During provision of social support to the patients, the author of this study played a major role as a listening friend (subject 1, 42.31%; subject 2, 33.33%), encouraging friend (subject

1, 23.08%; subject 2, 24.24%), and information-giving friend (subject 1, 15.38%; subject 2, 18.18%). Role as an unconditionally-accepting friend and a consoling friend were also enacted by the author, however not as much as the other three roles.

Results also showed that among two different sessions (see excerpts from subject 1 and 2) of social support giving process, there was similarity between social support technique used and social support given. Results also showed that *attending*, *reassuring*, *summarizing* were social support techniques that were appropriate for subject 1 and 2, in order to fulfill their needs for emotional and informational support. Furthermore, several roles that the author enacted,



Note. 1. listening friends, 2. consoling friends, 3. encouraging friends, 4. unconditionally-accepting friends, 5. information-sharing friends

Figure 2. Support given as intervention toward subject 1 and subject 2

namely as a listening friend, encouraging friend, and information-giving friend, were roles that were appropriate for subject 1 and 2, in order to fulfill their emotional and informational needs.

Overall, results revealed that the application of the three social support techniques (attending, reassuring, summarizing), and a number of roles enacted by the researcher (roles as a listening friend, an encouraging friend, and information-giving friend) were appropriate for fulfilling the patients' needs of emotional and informational support. It can be implied that the three social support techniques (attending, reassuring, summarizing) were able to fulfill subject 1's and subject 2's needs for emotional support (via roles as a listening, consoling, and encouraging friend during times of crisis) and informational support (via sharing of information related to the disease in general) (Nugraha, 2005). The notion that the subjects' needs had been fulfilled can be implied from the decreasing of stress symptoms as reported by the subjects. Since this article was intended as a follow-up to Nugraha's research (2005), it was suggested that this research should be followed by other studies, which may explain the cause, the dynamics, and the consequences of the patterns.

Although the application of emotional and informational support have not yet been established empirically, according to theory of stress proposed by Lazarus & Folkman (1984, in Schwarzer & Knoll, 2007), the internal processes experienced by subject 1 and subject 2 can be explained as this: Information given to the participants, via informational support, would affect cognitive appraisal of subject 1 and 2. Working in a mutualistic way with the researcher's unconditional acceptance and willingness to listen and to encourage, the information given to the participants might facilitate the emergence of a more positive cognitive appraisal from subject 1 and subject 2. Moreover, patients might obtain better understanding of the effects of daily activities toward any experienced stress symptoms (see interview excerpts of subject 1 and 2). This specific circumstance would, in turn, lead to decreasing stress symptoms. This finding showed that the research participants enacted a more adaptive coping style, compared to their previous coping styles. This finding was in accordance with Lazarus's & Folkman's (1984, in Schwarzer & Knoll, 2007) notion of three-step approach. This concept argues that social support is one of the sources that affects cognitive appraisal of a stressed individual. In this sense, coping is a product of cognitive appraisal. The more social support that is available for the individual, the more positive the cognitive appraisal will be. This, in turn, will lead to better

coping facilitation (step 1). There-fore, social support indirectly affects individual coping (via changes of cognitive appraisal) (step 2). Finally, this coping will induce various adaptational outputs from an individual (step 3). Therefore, it can be implied that this study provides empirical data that is in accordance by Schwarzer's and Leppin's notion (Schwarzer & Leppin, 1991, in Schwarzer & Knoll, 2007) that provision of social support facilitates coping. The mechanism of social support may also indirectly diminish the patients' complaints and stress symptoms, meanwhile simultaneously affecting the patients' coping processes.

This study also revealed that the effect of social support would be noticeable only after several sessions (subject 1 during session 8; subject 2 during session 6). Although building relationship phase has been passed, it became clear that the next stage (facilitating positive action) was an individual process.

Another lesson learned is that as research participants, lupus patients must be approached with great sensitivity. Although they have previously received informed consent prior to data collection, they must be prepared to face termination. This study revealed that it was not an easy process to do.

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(Appendices follow)

# Appendix A

Table 1 Excerpts From Interview and Observation Results of Subject 1

Exce	•	d Observation Results of Subject 1	
	Topic	Interview	Observation
1	History of disease	Has been ill for the past 2 years.	Amiable-looking, seemed happy to greet the researcher. Did not fully disclose the real feelings.
2	Change of lifestyle. Chronic headache.	Unable to do prolonged work in front computers. Must stop working. Restricted for travelling. Experienced daily headache. Often broke compliance to doctor's rules.	Seemed to be irritated with health condition.
3	Skills on baking cakes	Baking cakes as a hobby. Friends often admired the cakes made by this subject.	Seemed cheerful, happy, and self-confident.
4	Complaint of headache and difficulty to regulate emotion	Difficulty to restrain oneself when angry (worsening relationship with others) Subject expresses the need to learn ways to regulate emotions.	Seemed furious when telling the researcher about the social environment which, according to the subject, deprecates her. Relatively open during sharing of feelings.
5	The effect of difficulties experienced when regulating anger	Bad relationship with family and friends. Less chances for socializing.	Seemed to be angry and felt that she was misunderstood.  Confused about the cause of the problem.  Open during sharing of feelings.
6	Inconfidence of one's ability to refine oneself.	Perceives an impending failure due to personal limitations.  At the end of the session, subject stated that she	Seemed to be spirited when discussing ways to regulate anger.  Seemed to be more open and calmer when
7	Anxiety toward future events	did not fully actualize her potential.  Pessimistic toward future because she has not yet been working and has not yet been engaged in any romantic relationship.  Anxious that she will not be able to get a proper husband.  Feels useless to family and oneself.	discussing her problems.  Seemed sad and very serious when disclosing her problems.
8	Anxiety toward future events	Although not yet completely sure, the subject expressed the desire to persist on doing her hobby (baking cakes) in order to make money.  Subject felt calmer and different than before.	When discussing her future, subject began to been able to perceive different alternatives (to make money) so that she did not need to overly dependent on her lifesavings.
9	Plan to add income	Subject expressed no desire to stop looking for work, meanwhile persist in increasing her skills (of baking cakes) and in her effort to sell her cakes.  Subject reported that her headache has not been occurring for quite a while.	Seemed enthusiastic when designing action plan
10	Personal problems	Feeling desperate during relationship with a married man.  Subject expressed the fear of not being able to build any romantic relationship with any man besides her current boyfriend.  Subject expressed relief for being able to share her disturbing problems.	Open. Looked cheerful, sometimes shy.
11	Identifying sources of support.	Subject voluntarily withdrawn from her family because she did not want to become burden, even though she felt lonely. She hesitated to ask for help.	Calm and able to conclude, relatively quick, that she actually possesses wide social network.
12	Termination	Subject stated that she feel calmer and her self- confidence increasing.  Her frequent headache has been diminished significantly.	Subject expressed apology if she had offended the researcher.

# Appendix B

Tabel 2
Excerpts From Interview and Observation Results of Subject 1

	Topic	and Observation Results of Subject 1  Interview	Observation
1	History of disease	Subject has been ill for a long time, but the diagnostic	Seemed happy to greet the researcher.
		that she had lupus have had been made 2,5 years ago. Subject stated that she had accepted ("pasrah") her health condition.	Seemed to be relaxed and open during discussion of her illness. During sharing, her eyes looked glassy and then she
2	Change of lifestyle.	Subject stated the desire of being in full health again. Subject was unable to do activities that might be done	burst into tears. Seemed proud to show her house.
	Difficulty of getting	prior to her illness.	When narrating her activities, she seemed lost in
	into sleep.	Subject was active as a mountain climber and was an organizational activist in her college and her neighborhood. After being diagnoses as having lupus, she had to remain on her house.	thought many times and somewhat less enthusiastic.
3	Fear of not being	Often felt afraid of not being able to have children	Seemed sad, but sometimes irritated.
	able to have children. Sleep difficulty.	because she had experienced multiple miscarriages. Subject stated that she felt shy for disclosing her problems, and she asked for not being labeled as 'crybaby' ("cengeng").	Seemed to be hesitating at sharing her feelings; however she was more open than the previous session.
4	Sleep difficulty. Often disturbed the husband.	Subject complained about her sleep difficulty and irritation (because she saw that her husband was able to sleep soundly).  She felt that her husband misunderstood her condition. Subject asked what she must do in order to be able to	Seemed very uncomfortable with her condition. She often changed her seating postures. Seemed irritated when sharing that her husband did not understand her.
_	GI 11.00 1.	sleep soundly.	
5	Sleep difficulty. Often disturbed the husband.	Subject did not disclose her fear to her husband.  She was afraid that her self-disclosure (of her true feelings) might lead to a quarrel with her husband.  She felt lonely because she did not have any friends and was forced to wake her husband because she needed	Seemed somewhat uncomfortable and guilty of the present circumstance.
6	Sleep difficulty.	someone to talk to.  Subject made several attempts to induce sleepiness.	Seemed eager to try new attempts to induce deep sleep.
Ü	Often disturbed the husband.	Subject made attempt to disclose her fears to her husband within her role and function as a wife.	Seemed to be more confident and courageous to disclose her feelings to her husband.
7	Discussing results	Subject felt relieved after attempt to disclose her feelings to her husband.  She expressed feeling of happiness after received positive response from her husband.  Having been able to disclose her feeling, she was finally able to sleep longer.	Subject appeared to be calmer and more cheerful.
8	Marital relationship	Subject narrated her gaping relationship with her husband. She stated she would make more attempt to disclose her feelings to her husband.	Relatively open during sharing of feelings and fears.
9	Reported sensations of pain on her body.	(session was aborted because subject was reported of being ill)	Bruises on subject's body could be observed.
10	Positive and negative	King m)	Seemed hesitant when told about her positive aspects.
11	aspects of oneself. Identifying sources of support	Subject realized that she actually had considerable sources of support, albeit unused ones. She would make attempt to seek proper supports during times of need, and not carrying the burden alone.	Seemed calm and smiled a lot.
12	Termination	Subject expressed regret that the program has been terminated and she disclosed her hope of any future programs.  When given feedback about how she looks much better than before, subject said that she felt calmer.	Seemed a bit sad but calm during termination.