REVIEWS

The importance of resilience for treatment adhesion in patients with systemic lupus erythematosus

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Abstract

Resilience (RS) is a component of the psychological structure that helps in the process of tackling adverse situations such as catastrophes, traumas, and diseases. It has been described in the literature as an important psychological aspect that might assist patients with chronic diseases to cope with the disease process, thereby to better adapt to the dynamic complex of the disease, including changes in routines, acceptance of the disease and its limitations, and also to increase treatment adhesion. The objective of this study is to conduct a literature review on the general concepts of RS and to synthesize the knowledge gained through research on the contributions of RS to treatment adherence in patients with systemic lupus erythematosus (SLE). The research results have shown that the study of RS in patients with SLE is very recent and it could contribute to increase the coping skills, treatment adherence, and develop a positive mental attitude in patients, thereby to avoid risks and promote protection factors

Keywords: Resilience, systemic lupus erythematosus, chronic diseases

Introduction

Systemic lupus erythematosus (SLE) is a chronic, inflammatory, multisystemic, autoimmune rheumatic disease. The etiology of the disease is ambiguous, although there are data showing that genetic, hormonal, and environmental factors may play a role.[1-3] It affects all the organs and systems, especially the skin, joints, kidneys, and blood vessels, either concomitantly or successively.[4-11]

Studies investigating the impact of SLE on patient lives highlight fatigue and chronic pain, generally resulting from comorbidities, as the common manifestations of the disease that are extremely harmful to the patient.[12-15] Psychological manifestations, psychiatric disorders associated with the disease, limited quality-of-life, and inability to work are also reported in literature.[16-21]

The symptoms, generally described in the literature for abandoning work or daily life activities are pain, fatigue, disease activity, and symptoms of depression.[19]

It has been observed that patients with SLE need to adapt to the treatment and the situation of living, so as to accept the limitations imposed by the disease, and treatment adhesion is fundamental to prevent disease aggravation.[19] The concept of RS is applicable in such contexts. It refers to a universal unfixed capacity that permits the subject to prevent, minimize or overcome the noxious effects of the adversities and adapt to the new reality.[22-24]

The concept of resilience

The term resilience, derived from the Latin word '*resiliens*', means to jump backward, return, be impulsed, withdraw, curl-up, or break. The term is also associated with physics and engineering studies, and in these fields, it refers to the capacity of material to absorb energy without suffering permanent deformation.[25]

RS is referred in the literature as process that explain the overcoming of crises and adversities in individuals, groups and organizations.[25] Its incorporation into psychology, would explain why some individuals managed to survive

and attain well-being in their lives, even in situations of social, economic, and psychological adversities.[22] It is also a quality or a capacity of persons, individually or in group, to resist adverse situations without losing their initial balance, i.e., the ability to accommodate and rebalance constantly.[26] Therefore, psychological RS consists of the capacity to overcome adversities.[35, 36] However, it does not mean that the process aids the individual to leave the crisis unharmed.[25] Although the concept of RS is very subjective, it belongs to the structure of psychological development, and can be understood as a personal ability to face adversity, not in the sense of resisting, but of coping with it and successfully overcoming.[26]

Initial studies on RS were more on children and adolescents and the inter-occurrences in human development.[27] Currently, there are studies on different life phases from infancy to old age.[28] There are more recent studies involving RS and chronic diseases, including HIV, diabetes, rheumatoid arthritis, and SLE.[29-32, 19, 37] Although there have been relatively few studies involving RS and chronic diseases, they are not usually conclusive in considering RS as an important protection factor in confronting difficult life circumstances such as diagnosis and the process of chronic diseases.[33]

RS is discussed both as an innate or acquired attribute and an interactive, multifactor process involving individual aspects, environmental context, quantity and quality of vital life events, and the presence of risk and protection factors (Table1).[34] Risk factors are the events that appear as an obstacle at individual or environmental level and they may enhance the individuals' vulnerability to develop negative results. The risk factors should be considered as a process and not as a variable, and relating these factors with all kinds of negative life events increase the probability of the individual to develop physical, social or emotional problems. Some examples of risk factors would be: parents´ divorce, loss of loved ones, sexual/physical abuse against a child, poverty, holocaust, accidents and natural catastrophes, war and the process of sickness itself, especially in chronic diseases.[25]

The protection factors of RS are those with potential capacity to minimize the possible negative or dysfunctional effects of risk factors.[24] Regarding the protection factors, authors agree on the conditions of the individual himself (expectation of success in the future, sense of humor, optimism, autonomy, tolerance to suffering, assertiveness, emotional stability, engaging in activities, goal-directed behavior, problem-solving ability, assessment of experiences as challenges and not threats, good self-esteem), family conditions (quality of the interactions, loving and competent parents, good communication with children, cohesion, stability, consistency), and the support networks of the environment (a conflict tolerant environment, demonstration of recognition and affection, of the defined and realistic limits).[35]

In patients with chronic disease, treatment adhesion can be considered as an important protection behavior and RS as an important psychological factor that may help the subject to have a positive attitude to avoid the risk and promote the protection factors.[19] It is important to point out that the protection factors do not necessarily eliminate the risks, but act as mediators and protectors against the adversities to overcome them.[23] Thus, RS itself can be considered as a protection factor that would help the subject to overcome the adversities of life.[32]

RS is not a kind of protective shield that some individuals may have, but the possibility of internal flexibility that makes it possible to interact successfully with the outside medium, by modifying themselves in adaptive manner to face the adverse conflicts. RS would not be a rigid defense form, but rather a way of managing adverse external and internal circumstances that are always present throughout human development.[25] Moreover, it should not be confused with invulnerability, because it does not deal with absolute resistance to adversities.[35]

In the context of chronic sickness, RS is the individual's ability to deal with the disease, accepting its limitations, collaborating with treatment adhesion, readapting, and surviving positively.[36]

Resilience in SLE: contributions to treatment adhesion

The literature on RS in rheumatic diseases is very limited and it is even scarce when considering RS in SLE patients. RS has been described as an important psychological factor that assists in improving the patient´s quality of life and treatment adhesion, and to face the disease with positive readaptations. Treatment adhesion includes adhering to the treatment by accepting the disease with its limitations, and following the medical recommendations and preventive measures properly to avoid disease worsening.[19, 29-33, 38]

To better understand the importance of RS in SLE, it is important to discuss briefly on treatment adhesion. The usage of this terminology varies greatly in the literature, but in general, it could be defined as the extent to which patient complies with the medical recommendations and therapeutic plan, and executing a diet or lifestyle changes, as prescribed by the physician. The agreement between the patient and the physician on the treatment to be followed is also an important factor in the adhesion process.[38, 39] Treatment adhesion is fundamental in SLE because it may help to improve the patient´s quality of life by diminishing the impacts of the disease comorbidities as well as the physical and psychological symptoms.[38]

Recently, there has been a drastic decrease in the mortality rate due to SLE and this can be partly attributed to advances in treatment that delay the disease progress and minimize the damage. However, the complexity in treatment regimens impairs the treatment adhesion.[40] Several other reasons for non-treatment adhesion have been reported in the literature. Some of the intentional causes for non-adherence are insufficient physician-patient communication, the patient's beliefs, and collateral effects. Unintentional adhesion problems are circumstances beyond the patient's control such as lack of understanding, forgetfulness, etc.[40] Work alliance between physician and patient, characterized by good communication about the treatment goals and tasks, along with the confidence and understanding of the relationship, may contribute to improve treatment adhesion.[41] This is also an important ally to promote RS.[37]

Therefore, RS related to diseases should be considered on the basis of risk and protection factors. In SLE, non-treatment adhesion can be considered as the risk factor, in the behavioral sense.[19]

Adhesion to treatment and having a support system are considered as protection factors.[19] In patients with chronic disease such as SLE, treatment adhesion is an important protection behavior for disease-linked RS, because it helps in preventing disease worsening.[37] Therefore, non-adhesion can be considered as a risk behavior, because it may cause worsening of symptoms and increase the risk of hospitalisations.[19, 37-39] High RS scores are directly associated with better physical health and fewer symptoms, and inversely with depression and other psychiatric disturbances. It is also related to improvements in the quality of life.[42]

The cross-sectional study conducted on 40 SLE patients have demonstrated that RS was associated with the variables such as proper treatment adhesion ($P = 0.00006$), difficulty in following the treatment ($P = 0.00022$), seeking more information about SLE ($P = 0.00641$) and understanding SLE ($P = 0.00119$).[19]

The patients who followed the medication correctly tended to show high RS, in contrast to those who did not. Around 91% of the patients with low resilience were those who did not follow the treatment correctly. About 78% with medium RS and all with high RS followed the treatment correctly. Furthermore, the patients who found it difficult to follow the treatment tended to present low RS compared to those who did not tended to present high RS levels. All the patients who found it difficult to follow the treatment had low RS. Among those with medium RS, 52% did not find it difficult to follow the treatment and the result was same

Table 1: Behaviors considered as risk and protection factors in patients with SLE

Risk factors	Protection factors
Not following the treatment regimen and recommendations	Following the treatment regimen and recommendations
Not understanding the disease	Searching for information on the disease and understanding it
Not accepting limitations	Accept the limitations imposed by the disease
Not following the medical recommendations	Following the medical recommendations
Smoking	Not smoking
No protection against sunlight and heart disease control	Protection against sunlight and heart disease control
Not having a support network	Having a support network

for high RS.[19]

The patients who understood SLE tended to show high RS, compared to those who did not. Around 64% of the patients with low RS were those who did not understand SLE. Among those with medium RS, 52% understood in part and 83% of the patients who understood SLE demonstrated high RS.

Patients who searched for information on the disease, in addition to that given by the physicians showed high RS. Around 73% of the patients with low RS and 39% of the subjects with medium RS did not try to find more information about SLE. About 83% of patients with high RS tried to find more about SLE.

Assessment of RS in 45 SLE patients, using the Wagnild and Young and Mini International Neuropsychiatric scales, showed that the corresponding percentage of subjects with low (<121), medium (between 121 and 146), and high RS (>146) scores were 8.9%, 71%, and 20% respectively. The study also found that patients over 35 years of age had the highest RS scores and those at risk of committing suicide presented the lowest RS scores, possibly due to high level of depression. Thus, it could be concluded that identifying risk and protective factors is important for developing psychological support strategies.[32]

RS may also help the patients to deal with daily stress, thereby to overcome the disease-related adversities. The assessment of RS and the self-reported treatment adhesion behaviors in 40 SLE patients showed that 27.5% of the patients presented low RS, 57.5% moderate, and 15% high RS. These findings indicate that most of the patients accept and adapt to the reality of coping with SLE, and manage to follow the treatment properly.[19]

Furthermore, the study reported that patients with high RS continued the work and daily activities, irrespective of the disease.[19] The literature reports indicate that most of the symptoms of SLE interfere with several aspects of the patient´s life, which may lead to abandoning of regular employment and daily activities.[20, 43-45] However, RS may be a contributing factor that assists patients manage or alter their lifestyle, and maintain an efficacious performance in daily activities, in spite of the adversities or stress.[23, 24, 32]

In SLE, treatment adhesion is a determinant factor for absence of disease activity and not receiving the medication is an important cause of non-adhesion.[40] Thus, it is could be concluded that high RS allows the patient to have a positive attitude for accepting the disease, and follow the recommendations and treatment correctly.[19, 40]

Understanding the disease is also crucial for treatment compliance, because even the most active patients, when they are not well informed and do not establish a link with the health service, have a greater probability of not accepting the suggested treatment.[46] This holds good for SLE patients also, because understanding the disease help them to avoid the associated risk behaviors such as exposure to the sun, smoking, irregular appointments with physician, and treatment non-compliance. It may also help them to promote protection factors. RS can serve as an important protection factor for SLE patients, contributing to the process of treatment adhesion and to achieve better physical health, fewer symptoms, and improved quality of life.[42, 19, 32]

Understanding the significance of RS in SLE management reiterates the need for adopting strategies that promote RS in such patients, thereby to attain better treatment and health outcomes.[37] These include educational, psychosocial, and self-care interventions to promote mental resilience, positive coping strategies, self-advocacy, and capacities for social participation.[37] Therefore, it is critical to consider the dynamic complexity related to the promotion of RS in SLE patients including the role of environmental, psychological, social, and internal factors as well as the articulation of the risk and protection factors.[11, 32, 33]

Government policies to improve the access of health service are one of the external factors facilitating treatment adherence. The government and allied institutions should focus more on educational activities to enhance patients' understanding about the disease. Such activities assist in increasing awareness of self-care and how to avoid risk factors and acquire protective behaviors.[19, 37]

Regarding the psychological and social factors, the literature reports that the support and a confident relationship with the physician are important to manage chronic diseases such as cancer and SLE.[37, 47] Medical professionals and allied institutions should implant a more open assistance in providing information to patients on the disease, types of care and treatment, taking into consideration their schooling and culture, to promote RS. The encouragement and support that they receive from

their family and friends are also reported as factors that permit patients to feel more motivated to persevere and cope better with the disease.[37, 47]

Internal factors that aids in building RS are self-efficacy, sense of humor, and having intellectual capacities such as the potential for insight, self-esteem, and autonomy.[22, 23, 30] Self-care and developing strategies to cope positively, and self-defence are also reported as important aspects to promote RS.[37]

Conclusion

RS is an important aspect of the psychological structure that may confer various benefits to patients with chronic diseases. Patients with high RS tend to have a positive attitude to accept the limitations of the disease and, promote protection factors, and avoid the risk factors. To achieve this goal, the patient should adopt a healthy lifestyle, including modification in the diet, regular physical exercise, stress and excess work control, and avoiding events that may trigger or aggravate symptoms. Support and psychological assistance from healthcare professionals and allied groups are important for SLE management and they may help to develop individual potentialities to promote RS.

Competing interests
The authors declare that they have no competing interests.

Disclosure
None

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