



## **The Experience of Scleroderma, Stressful Life Events, Attachment, Post Traumatic Stress Symptoms and Resilience.**

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### *Acknowledgements*

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### *Aim*

The main purpose of the study was to investigate the relationship between psychological factors that may impede functioning of the immune system and Scleroderma. The factors included stressful life events, attachment, anxiety disorders (such as post traumatic stress), depression and low resilience. Several other factors such as a change of lifestyle, type of scleroderma and pituitary adenoma were also investigated.

Research (Every & Lating, 2002) to date has identified relationships between stress and medical illness. The current study considered quality of attachment and stressful events as measures of stress; resilience as a measure of coping in stressful situations, and the impact these aspects may have on an individual's psychological (post traumatic stress, anxiety and depression) and physical health (scleroderma). A short description of the factors that were examined in the study, are presented below.

### *The Immune System and Scleroderma*

A healthy immune system protects the body from antigens such as viruses and bacteria (Cohen & Herbert, 1996). Stress induced changes in the immune system may create an over-reactive system that fails to discriminate between the self and these antigens; in this situation autoimmunity occurs (Cassidy, 1999). Scleroderma is a chronic and often progressive disease that affects the circulation, causes inflammation and autoimmunity. Scleroderma is the result of

an individual's immune system attacking their own body causing scarring (fibrosis) and impeding normal functioning of the skin, joints, blood vessels, lungs and internal organs (Etkins & Mills, 2005).

### *Stress Response and Stressors*

The body's stress response is a defence mechanism that is designed to protect the body, however when the body's reactions become excessive and the individual is unable to adapt to the stress situation, an ongoing state of hyperarousal may be experienced and the body's defences may initiate a disease process (e.g., Every & Lating, 2002; Selye, 1976). Stressors are described as any physical or psychological stimuli that can produce a stress response (Selye). Stressors can vary in intensity. Individual's response to stressors mostly occurs as a result of conditioning. Stressors do not always elicit the same response for individuals, due to genetic predispositions, age and gender or exposure to environmental factors such as social stressors, pollutants and drug treatments. There are two types of stressors that act on the body, direct stressors and indirect stressors. Direct stressors such as extreme heat and potent acids, will damage the body regardless of the body's defensive response to the stress. Indirect stressors, such as emotional, immunological and inflammatory responses may elicit excessive arousal reactions, dependant on the intensity of the individual's response to the stressor (e.g., Every & Lating, 2002; Selye).

### *Attachment*

Attachment theory describes the interactions between a child and his or her primary caregiver. Attachment is described as a protective mechanism that is triggered when a child feels threatened (Bowlby 1969, 1997) and may result in lifelong patterns of response to threat (Crittenden, 2000). Adult feelings of security and emotional responses reflect attachment behaviours learnt in early childhood. Accessible and responsive attachment figures in adulthood facilitate secure attachment, while unavailable attachment figures may create attachment related fears resulting in insecure attachment styles and anxiety disorders (Miculinker & Shaver, 2007). Stressful attachment interactions may contribute to the development of insecure attachment styles associated with an inability to regulate stress, control emotions and increase vulnerability to stress and disease (Maunder & Hunter 2001).

## *Anxiety and Depression*

Anxiety is described as a normal response to a threatening situation. However, when the level of response to a specific event or stressor becomes excessive and the individual experiences difficulty controlling excessive worry in relation to these fears an anxiety disorder may develop (Hunt & Jarry, 1997). Several factors have been implicated in the development of anxiety and depression, such as, attachment stress, adverse life events, genetic predispositions and immune dysfunction (e.g., Arnetz & Ekman, 2006; Miculinker & Shaver, 2007; Schore 2000). Symptoms of depression include feelings of sadness and hopelessness, loss of interest or pleasure in activities, fatigue, an increase or decrease in appetite and weight, along with sleep and concentration problems, feelings of worthlessness and inappropriate guilt (American Psychiatric Association, 2000). The development of depression and multiple subtypes of anxiety, including post traumatic stress have been associated with maladaptive responses to prolonged stress, which can have a negative impact on the interactions of the neural, endocrine, and immune systems (Arnetz & Ekman, 2006).

## *Post Traumatic Stress Disorder (PTSD)*

PTSD is described as an anxiety disorder that develops as a delayed response after witnessing or experiencing a traumatic event involving actual or threatened death or serious injury to the self or others. It is characterised by helplessness, intense fear, or horror. PTSD symptoms are more severe when more time has elapsed between the event and onset of PTSD (American Psychiatric Association, 2000). PTSD does not occur immediately after the traumatic event occurs. The development of PTSD depends on an individual's ability to overcome the symptoms associated with trauma exposure (Cassidy & Shaver, 1996; McFarlane & Yehuda, 1996). PTSD symptoms include recurrent distressing memories or flashbacks caused by reminders of the trauma, reliving the trauma, recurring nightmares associated with the trauma, persistent avoidance of thoughts, feelings, people and places associated with the trauma, an inability to recall an important aspect of the trauma, a numbing of emotions, irritability, anger, poor concentration and/or startled reactions (American Psychiatric Association).

## *Resilience*

Psychological resilience is described as a flexible and adaptive behaviour that enables the individual to successfully recover from stressful life events (Bonanno, Rennieke, & Dekel,

2003). Resiliency has been described as an “adaptive response” that varies depending on the level of exposure to a threat (Richman & Fraser, 2000). Resilient individuals tend to experience mild, temporary disruptions in functioning and in time exhibit relatively stable levels of healthy adjustment to the stressor due to adaptive coping strategies (e.g., Bonanno et al. 2003; Cassidy & Shaver 1996). Individuals low in psychological resilience, tend to experience difficulty regulating negative emotions and exhibit heightened reactivity to everyday stress situations (e.g., McFarlane & Yehuda, 1996; Ong, Bergeman, Bisconti, & Wallace, 2006).

### *Participants*

Two hundred and eighty three individual's, from Australia, the United Kingdom, Europe and the United States of America completed the Scleroderma questionnaire. A number of individual's were excluded due to incomplete information. Of the remaining 239 people, 209 were female (87.8%) and 29 (12.2%) were male. A majority of people (48.7%), reported being diagnosed with limited systemic sclerosis (CREST), 37.6%, reported a diagnosis of diffuse systemic sclerosis and 8.4%. reported localised (linear/morphea).

## Findings

### *Post Traumatic Stress Symptoms*

Seventy percent of people in the study experienced Post Traumatic Stress Symptoms before diagnosis of Scleroderma and 31.5% reported currently experiencing these symptoms. Reporting of Stressful Life Events, Pituitary Adenoma's, Depression and Anxiety Disorders in the current study was significantly higher than rates reported in the general population. Findings also revealed that individuals who experienced more Stressful Life Events and who exhibited an Insecure Attachment Style were more likely to have experienced elevated Post Traumatic Stress symptoms before diagnosis of Scleroderma.

### *Severity of Scleroderma Symptoms*

Individuals diagnosed with an Anxiety Disorder/and or Depression, who reported a lower ability to cope with stressful situations (Resilience) were more likely to experience more Severe Scleroderma Symptoms. Health related information showed that people, who had more Scleroderma Operations and had been diagnosed with other Autoimmune Diseases, also experienced more Severe Scleroderma Symptoms.

Differences were found for people diagnosed with Diffused and Limited Sclerosis. For those individuals diagnosed with Diffuse Sclerosis who had received a diagnosis of Post Traumatic Stress Disorder (before diagnosis of Scleroderma) and who were exposed to a Stressful Life Event at the time they were diagnosed with Scleroderma were more likely to experience more severe Scleroderma symptoms. Individuals diagnosed with Limited Sclerosis (CREST) who had a diagnosis of Depression and/or an Anxiety Disorder before diagnosis of Scleroderma, Lower Resilience and more Operations as a result of Scleroderma were more likely to experience more Severe Scleroderma Symptoms.

#### *Lower Severity of Scleroderma Symptoms*

Some people who reported a Change of Lifestyle and a reduction in Scleroderma Symptom Severity stated they had experienced less stress by changing or ceasing stressful employment situations or moving out of stressful relationships (psychological stressors). Others reported changing how they cared for themselves to reduce exposure to cold (Raynauds: physical stressors). Many participants however did not indicate how they changed their lifestyle; further research in this area may be beneficial.

#### Implications

People in the current study reported exposure to stressors, insecure attachment and Post Traumatic Stress symptoms before they were diagnosed with Scleroderma. These factors have been implicated in the development of autoimmune disease (Schoe, 2000) and therefore may be associated with the onset of Scleroderma. Exposure to multiple stressors have been associated with ineffective coping strategies for managing stress, (Every & Lating, 2002) depression, anxiety and immune dysfunction (e.g., Arnetz & Ekman, 2006; Schoe 2000). In the current study individuals who reported ineffective copying strategies for dealing with stressful situations and who reported experiencing depression and /or anxiety (before diagnosis of scleroderma) tended to experience more Severe Scleroderma Symptoms.

Different factors were implicated in the experience of Diffuse and Limited Sclerosis. For Diffuse Sclerosis people who reported a diagnosis of Post Traumatic Stress Disorder and exposure to the stressor when diagnosed with Scleroderma had more severe Scleroderma Symptoms. While those with Limited Sclerosis demonstrated a lack of coping strategies associated with Low Resilience and a diagnosis of Anxiety and/or Depression as psychological predictors of Severity of Scleroderma.

The final implication drawn from the findings of the current study concerns positive changes in lifestyle. Strategies that reduce stress have been reported in the literature as reducing arousal and improving overall health outcomes, by slowing the disease process and reducing pain (e.g., Hagershaun 2004; Nassan, Tein & Fritz, 2008). These factors may explain the lower levels of Severity of Scleroderma Symptoms associated with a change of lifestyle and may be beneficial strategies for reducing Scleroderma Symptom Severity.

### Summary/Conclusions

In summary, the findings for the present sample suggested that participants experienced higher levels of exposure to psychosocial stressors than the general population. Exposure to stressors in the current sample was predictive of elevated levels of Post Traumatic Stress Symptoms before diagnosis of Scleroderma. Post Traumatic Stress Symptoms have been implicated in immune dysfunction as well as autoimmunity (Kiecolt-Glaser & Glaser, 2002) and therefore may be associated with the onset of Scleroderma. Low Resilience, Anxiety Disorders and Depression have also been associated with Post Traumatic Stress (e.g., Every & Lating, 2002; Kiecolt-Glaser & Glaser) and were predictive in the current sample of Severity of Scleroderma. Differences in individual exposure to Stressful Life Events, adaption to stressors and stress management strategies, may account for the variance in symptoms and symptom severity found in those suffering from Scleroderma in the current study.

### Recommendations

*Stress Management Counselling.* A majority of people in the study reported experiencing a high level of exposure to Stressful Life Events and for some individuals this exposure resulted in the development of ineffective coping strategies for managing stress and more Severe Scleroderma Symptoms. It may therefore be beneficial for people who have experienced high levels of exposure to Stressful Life Events to receive counselling in stress management techniques to develop more effective coping strategies, which in turn, may reduce the Severity of their Scleroderma Symptoms.

*Lifestyle Strategies.* Some people reported lower Scleroderma Symptom Severity after making positive changes to their lifestyle. These people stated they had experienced stress reduction by leaving stressful relationships or ceasing stressful employment situations (psychological stressors). Others reported changing how they cared for themselves by reducing exposure to cold

(Raynauds: physical stressors). A number of other strategies for lifestyle change may also be beneficial; these include meditation, relaxation and breathing techniques, exercise, social support, a balanced diet and lifestyle.

*Psychological Intervention.* People who have been diagnosed with a chronic illness may also experience depression and anxiety. As Depression and Anxiety predicted more Severe Scleroderma Symptoms in this study it is suggested that people with Scleroderma check for symptoms associated with these conditions. Lifeline and Beyond Blue have websites (listed below) with further information about these conditions. It is recommended, that those people who are experiencing Depression and Anxiety symptoms and who reported current Post Traumatic Stress symptoms speak to their doctor. Please see the attached scale which was used to measure PTSD symptoms, to ascertain whether you reported currently experiencing PTSD symptoms.

#### Websites

*A list of psychological services can be accessed at the following website.*

Australian Psychological Society: [www.psychology.org.au/ReferralService/About](http://www.psychology.org.au/ReferralService/About)

*Information for depression and anxiety is available at the following Websites*

Beyondblue: [www.beyondblue.org.au](http://www.beyondblue.org.au)

Lifeline: [www.justask.org.au](http://www.justask.org.au)

If you have any further questions about this study please contact either myself, Karen Kearney or Dr. Dee Bartrum at [dbartrum@bond.edu.au](mailto:dbartrum@bond.edu.au)

#### *Currently Experiencing PTSD Symptoms*

The questionnaire contained statements in relation to the Stressful Life Events Scale; an example of a question (Q. 15) from this scale is included. Participants then answered questions about how these events (which occurred before they were diagnosed with Scleroderma) made them feel, these questions are included below Q 15. Those people who answered yes to question 23; “*Do you still experience any of the stated symptoms*” are currently experiencing PTSD symptoms. This scale measures PTSD symptoms only and is not a diagnosis of PTSD. A psychologist will be able to assess your symptoms and verify diagnosis.

*Stressful Life Events Questionnaire (example question)*

**15. Have you ever been in any other situation that was extremely frightening or horrifying, or one in which you felt extremely helpless, that you haven't reported?**

Yes

No

If yes, at what age? \_\_\_\_\_

Please describe. \_\_\_\_\_

*Impact of Event Scale (PTSD Symptoms before diagnosis of Scleroderma)*

**Please respond to the following questions with the above event/s in mind.**

	<b>Not at all</b>	<b>A little true</b>	<b>Moderately true</b>	<b>Quite true</b>	<b>Completely true</b>
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I felt irritable and angry	0	1	2	3	4
5. I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
6. I thought about it when I didn't mean to	0	1	2	3	4
7. I felt as if it hadn't happened or wasn't real	0	1	2	3	4
8. I stayed away from reminders about it .	0	1	2	3	4
9. Pictures about it popped into my mind	0	1	2	3	4
10. I was jumpy and easily startled	0	0	2	3	4
11. I tried not to think about it	0	1	2	3	4
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	2	3	4
13. My feelings about it were kind of numb	0	1	2	3	4

14. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
15. I had trouble falling asleep	0	1	2	3	4
16. I had waves of strong feelings about it	0	1	2	3	4
17. I tried to remove it from my memory	0	1	2	3	4
18. I had trouble concentrating	0	1	2	3	4
19. Reminders of it caused me to have physical reactions such as sweating, trouble breathing, nausea, pounding heart	0	1	2	3	4
20. I had dreams about it	0	1	2	3	4
21. I felt watchful or on-guard	0	1	2	3	4
22. I tried not to talk about it	0	1	2	3	4

*Currently Experiencing Post Traumatic Symptoms*

23. Do you still experience any of the above symptoms.  Yes

If yes please list each by circling the corresponding number.  No

4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22

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