"PUNISHMENT FOR MY SINS," "DIET PEPSI," OR "BAD GENES": PERCEIVED CAUSES OF AUTOIMMUNE DISEASES
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Abstract
Autoimmune diseases are the fourth most common type of chronic illness yet the medical causes of the diseases remain largely unknown. Individuals who are diagnosed with autoimmune diseases often face many psychological consequences as a result of their disease including feelings of isolation, stress, coping with the cycles of relapse and remission, lengthy and ambiguous diagnostic processes, anxiety, and depression.

The current study was part of a larger mixed-method study that included online surveys assessing disease severity, depression, self-efficacy, social support, positive well-being, and health-promoting behaviors. Participants were completing open-ended questions asking, "What do you think caused your autoimmune disease?" and "Have you been given a medical explanation for the cause of your disease?"

Participants included 175 individuals with connective tissue or musculoskeletal autoimmune diseases and ranged in age from 18-84 years. The most common diagnoses were rheumatoid arthritis, multiple sclerosis, systemic lupus erythematosus, and myasthenia.

A content analysis of the open-ended questions revealed that many participants were unsure why they were diagnosed with an autoimmune disease. Participants who had received a medical reason for their diagnosis often expressed a belief that the reason differed from what they were told by their doctors. In addition, some participants blamed themselves for their disease, even when they were not contributing to the medical information they had received. Lifestyle choices like dieting or working too hard were also blamed reasons. The most common explanations were genes, environmental causes, viral or bacterial causes, medications used, and spiritual beliefs.

Background
Why study autoimmune diseases?
• Most common type of chronic illness
• Medical causes remain largely unknown
• Autoimmune disease more frequently found in women
• Diagnosis often results in isolation, stress, coping, lengthy/ambiguous diagnoses, anxiety, depression
• Periods of relapse and remission can contribute to psychosocial difficulties
• Psychological consequences often result from perceived cause, especially when individuals blame themselves

Review of the literature
- Participants with Rheumatoid Arthritis, Global/International Populations were compared with community controls, showing depression (Dakic et al., 1994).
- Participants with adverse reactions to daily stress or control, showed depression (Matsuda et al., 1999).
- Participants with greater feelings of uncontrolability resulted in worse hypertension and depression (Dakic & Moore, 1994).
- A group of patients with Rheumatoid Arthritis, Helplessness and negative outcome expectancies predicted future hopelessness and depression (Drake & Woodland, 2002).
- Controllability proved to be highly important for Rheumatoid Arthritis patients (Friedman & Symonds, 1992).
- People who are diagnosed with rheumatological conditions are more depressed than the general population (Mangels et al., 2002).
- People who believe they can control the relationship between depression and pain report greater depression and pain (Mangels et al., 2002).
- People with more severe symptoms are more depressed (O'Connor & Hackett, 2002).
- People who are diagnosed with autoimmune disease for longer periods of time and with more severe symptoms have decreased social support (Poyntz et al., 2002).

Design of the Study
- Procedure:
  - This study was designed to investigate the psychosocial reactions of individuals with autoimmune diseases.
  - Descriptive study with self-report survey data
  - Included a range of participants with connective tissue or musculoskeletal autoimmune diseases listed in the table below
  - Survey: used via self-service, online method, links to autoimmune disease websites, and e-mails from clinics
  - Physicians at the Clinical Care Center at the National Institute of Arthritis and Musculoskeletal and Skin Diseases encouraged patients to participate
- Participants: wide range of participants, some of participation, written consent
- Included both qualitative and quantitative data

Qualitative Analysis
- Team of three coders with one auditor
- Three individuals were responsible for independently coding data for each participant
- Three coders noted any of the three questions
- Coding was conducted using qualitative coding

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Participants
- 175 individuals, ages 18-84
- 95% of the participants were white; 90% of the participants were female
- Wide range of diagnoses, occupations, educational levels, and incomes

Participant's responses to the open-ended questions:
- "What do you think caused your autoimmune disease?"
- "Have you been given a medical explanation for the cause of your disease?"

Methods
- Thematic coding of qualitative data

Results
- People believed a variety of ideas as to what caused their autoimmune disease.
- A majority of people believed it was caused by genes, psychological stress, stress on the body, or some didn't know.
- A variety of reasons were expressed for the cause of an autoimmune disease: Some people took the genetic approach; "Heredity and I think I had an interest in genetics" or, "Bad genes" into, "The disease runs in families; my father had autoimmune disease." Others chose to blame psychological stress: "Taking too much for too long a time to take over" or, "Prolonged stress" and "Stress." Others chose to blame the stress on the body as an "I think it was triggered by pneumonia" or, "I had many childhood diseases" or, "Years of playing soccer" as well as "Give birth to my second son triggered it." Some blame various medical interventions; "I was triggered by a stress" or, "I was taught that it was psychologically related or, "It's all in the mind." Others blame environmental factors; "Type of area where I was born and raised" along with, "Extremely sunny on a Caribbean holiday" and, "The forests there are surrounded by itself and the environment we live in." Still others, just didn't know what the cause was: "I wish I knew" and, "God only knows" or, "I have no idea, just don't know."