



Questions & Answers

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Why did CDC conduct this study?

CDC had received inquiries regarding the cause of an unexplained skin condition, commonly referred to as Morgellons. Given the number of reports in 2006–2009, CDC, together with Kaiser Permanente (KP) - Northern California, and the Armed Forces Institute of Pathology, began a measured and thorough scientific investigation that would offer the best chance for finding useful answers. The results of the study comprise the first comprehensive clinical and epidemiologic description of a defined group of patients with this condition.

What were the goals of the study?

The primary goals of the study were to learn more about

- who may be affected with this condition, referred to as unexplained dermatopathy in the study;
- the symptoms persons with the condition were having;
- whether persons affected had other medical conditions that could be contributing to their illness; and
- whether there was any evidence that this condition was caused by an infectious disease or substance in the environment.

The study sought to

- document what symptoms were associated with this condition;
- determine whether certain groups of people were more affected than others;
- examine skin samples from affected patients;
- identify the composition of any fibers or threads obtained from the lesions of persons with the condition; and
- estimate rates of how common the illness was among the study population.

What did the study find?

The study results showed that this condition appears to be uncommon; 115 patients were identified

among more than one million KP - Northern California plan participants that fit the criteria used to identify an unexplained dermopathy case. Among persons in the KP – Northern California system there were 3.65 cases per 100,000 enrollees. This means fewer than four out of 100,000 people seek medical attention for this condition.

Persons who reported symptoms were most commonly

- women (84%)
- Caucasian (77%) and
- between 45-64 years old (64% were in this age group).

In addition to reporting fibers or other foreign material in their skin, almost all study participants had what they referred to as disturbing skin sensations. Other symptoms commonly reported included

- fatigue (70%)
- sleep disturbance (60%)
- muscle aches (71%)
- joint pain (69%)
- hair loss (63%), and
- neurologic symptoms such as difficulty finding words (64%) and decreased memory (59%).

Other illnesses that had been previously diagnosed by a physician and were reported by patients included

- hypertension (39%)
- allergies (30%)
- arthritis (32%)
- infectious skin conditions such as scabies (20%), or
- psychiatric illnesses including
 - depression (32%)
 - anxiety (19%) or
 - attention deficit disorder (9%).

Of 62 skin specimens examined

- the most common abnormality was sun damage, a skin change from sun exposure and aging;
- many of the skin sores showed evidence of scratching or chronic irritation.
- 16 of the biopsy specimens examined were identified as containing foreign material, mostly cotton or talc, polyester or silicone;
- 15 of the skin-lesion specimens cultured grew common skin bacteria (*Staphylococcus "staph"*) or (*Streptococcus "strep"*), from breaks in the skin.

Of 36 patients who completed neuropsychological testing using the Personality Assessment Inventory (PAI), a multi-scale test of psychological functioning that assesses personality and psychopathology:

- 63% had a high score for somatic concerns (an indicator of preoccupation with health issues); and
- 11% had a high score for depression.

Few patients had abnormalities detected by blood testing:

- none had evidence of Lyme disease; and
- 50% had a hair sample that tested positive for one or more commonly abused drugs.

Did the study find a cause for this condition?

The study did not identify a definite cause of the skin symptoms reported by patients. Researchers found nothing to indicate an infectious source or environmental link. Many patients had underlying medical, including psychiatric, conditions that could be treated to possibly reduce their skin symptoms. This unexplained condition has many similarities to a recognized medical illness known as delusional parasitosis (in which persons believe their skin is infested with parasites).

We were not able to conclude based on this study whether this unexplained dermatopathy represents a new condition, as has been proposed by those who use the term Morgellons, or wider recognition of an existing condition such as delusional parasitosis. In the absence of an established cause or treatment, patients with this unexplained condition may benefit from treatment for co-existing medical conditions and/or those recommended for similar conditions such as delusional parasitosis.

Is this condition contagious?

There was no evidence that this is a contagious illness. The skin lesions were not caused by any known infection, as shown by negative results from the large number of skin, blood, and culture tests performed. When viewed under a microscope, the lesions did not show evidence typical of a primary infection.

What can CDC say about this condition, based on what was learned from the study?

Based on the study results, CDC finds:

- The condition appears to be uncommon, most frequently affecting middle-aged Caucasian women.
- There is no evidence to suggest an infectious cause, nor is there an indication of an environmental link. Laboratory analysis of fiber and foreign materials found in skin lesions were mostly cotton, typically found in clothing or bandages.
- About half of the study participants had one or more co-existing medical, including psychiatric, illnesses. Treatment of these illnesses may improve symptoms.
- This unexplained condition has many similarities to a psychiatric condition in which patients have unusual skin sensations that they attribute to an infectious cause, known as delusional parasitosis or delusional infestation.

Is this unexplained condition a mental illness?

We cannot say for certain that this is a mental illness, as the study was not specifically designed to address this question.

The study results do show that in neuropsychological testing, a substantial number of study participants were found to have test results suggestive of one or more psychiatric or addictive conditions, including depression, somatic concerns (an indicator of preoccupation with health issues), and drug use.

What methods were used to study this condition?

Patients in the study underwent in-depth interviews, physical exams, hair-sample testing for drug abuse, tests of self-perceived quality of life, and neuropsychological testing. Blood samples and skin-biopsy specimens underwent extensive microscopic and chemical analyses. The residences of patients were mapped using Geographic Information Systems (GIS) to look for clustering, or grouping, of cases.

Who was eligible to participate in the study?

Eligible participants were required to live in the Northern California area, were at least 13 years old, had been a health plan member of KP - Northern California from July 2006 through December 2007, and had compatible signs and symptoms of the condition as described in the study protocol. Participant selection followed a set protocol, and not all persons who identified themselves as having signs or symptoms of this condition were eligible to participate in the study.

Why did CDC select KP - Northern California as a partner for the study?

Several factors led CDC to select KP - Northern California as a partner in this study:

- CDC sought a location and an organization that would likely have an adequate number of affected persons to be able to conduct a careful investigation. KP - Northern California is located in a geographic area in which self-reported cases of this condition are concentrated;
- KP - Northern California comprises a large and representative proportion of the population in the Northern California area; and
- KP - Northern California has electronic health records that allowed a systematic method for identifying persons who may have this condition.

Why did it take so long for the results to be released?

The goal was to conduct a comprehensive investigation that described the condition and looked for a wide variety of potential infectious disease causes and possible underlying medical causes. Considerable time, resources, and effort were spent to conduct the study, analyze the data, and ensure the findings met the standard for publication in a peer-reviewed journal.

Publication in a peer-reviewed journal is a critical step in scientific research, as it

- allows additional experts to review the study methods and results to ensure its quality and appropriateness, and
- contributes to the accepted scientific body of evidence that informs our understanding.

The peer-review journal process is necessarily deliberate and precludes any advance release of the study.

We recognize that patients and their families affected by this condition have anxiously been awaiting the release of the study report. Investigators worked to make the study report available as quickly as possible without compromising the scientific methods or the peer-review publication process.

What are some of the study limitations?

It is not certain how well patients in this study represented persons with similar symptoms in other parts of the United States or the world, because patients were identified through a single, large healthcare organization in one region of the United States. However, persons who receive care in this system have been shown in previous studies to have characteristics similar to the U.S. population, and they are considered to be a good representation of the overall U.S. population.

The study was not designed to assess treatment interventions that might help patients with these symptoms. Additional studies could more fully describe patients with this condition and assess the extent to which treatment of concurrent medical conditions identified in the study may improve or eliminate symptoms.

Additional study limitations are addressed in the paper.

What about any follow-up studies?

CDC is not planning any further studies or activities related to this unexplained condition. This

was the largest and most comprehensive study to date, and no common underlying medical condition or infectious source was identified. The study findings do offer useful information and insights, including ruling out an infectious cause of this condition. This is important information to help guide persons who suffer from this conditions and their health care providers, when considering treatment options. In the absence of an established cause or treatment, patients with this unexplained condition may benefit from treatment for co-existing medical conditions and/or those recommended for similar conditions such as delusional infestation.

Someone I know is suffering from a condition similar to what is described in the study. Where can I go for help?

Individuals who believe they have skin conditions similar to what was described here should contact a licensed healthcare provider for appropriate evaluation and treatment.

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