

The Patient with Sensory Loss¹

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Medical training prepares the professional for finding means of relieving pain and discomfort in patients even when the cause of the pain has not been identified. Pain is the symptom which most motivates both doctor and patient to find a solution as quickly as possible. When the pain is eliminated both feel as though the disease itself is under control and recovery is imminent.

Pain is a signal. Its purpose is to make us aware of a real situation which is harmful or may become harmful unless action is taken. If our sensation has been diminished below protective levels, there is no mechanism in our body to replace it. The chance of injury and the likelihood of continuing to traumatize an injured part are greatly increased.

The mycobacteria which cause leprosy live in the tissues near the body's surface, and destroy nerves in the superficial tissues. With the resultant sensory loss, a person can be injured, even severely, and feel no pain. If pain is felt, it is not in proportion to the extent of injury. This loss of pain sensation alters the behavior of both physician and patient. Their motivation in healing and preventing injury may be subtly diminished.

People who work with the chronic ulcerations of leprosy on a regular basis are often pessimistic (⁹). With the absence of pain, it can often appear as though the insensitive patient's every action is directed toward keeping a foot or hand wound open. It can be difficult, at times, for the medical practitioner not to think of them as totally non-compliant or irresponsible. The most revealing statement concerning this problem is often stated by the patients themselves. "... but it doesn't hurt."

Recent studies have shown touch to be as essential to our state of well-being as our

senses of sight or hearing (^{1,4,11}). Our sense of touch is a vital information source about the character of the objects in our environment (⁵). When the object we touch is another human being then how, where, when, and why we touch them tells this person something about us and how we feel about them (¹⁰). When the object we touch feels threatening, we withdraw our touch as a means of self-protection.

Since so many medical practitioners have difficulty in treating patients with sensory loss, we developed a questionnaire to evaluate the experience of the patients who live with this problem daily.

METHODS

During the last six months of 1983, 100 leprosy patients were interviewed at the National Hansen's Disease Center in Carville, Louisiana, U.S.A. All of the interviews were conducted by the authors, and each interviewed 50 patients. Each patient was asked to answer the same 25 questions. In most cases, for clarity to the patient, each question was asked several different ways. All responses were recorded by the interviewers, and after the completion of all interviews, the responses were placed into categories to facilitate data compilation.

Of the 100 patients interviewed, 38 were females and 62 were males, ranging in age from 11-76 (average age = 45). The patients had had Hansen's disease for an average of 32 years (range = 2-69 years). Fifty-four of the patients were married, 27 were single, 12 were widowed, and 9 were divorced. The average patient had attended eight years of school (range 0-21). There were 69 Caucasians, 16 Blacks, and 15 Orientals originating from the following geographical areas: U.S.A., 34; Mexico, 16; Pacific Islands, 8; Caribbean, 7; Asia, 10; South America, 3; Europe, 3; Central America, 2; and the Middle East, 1.

RESULTS

Four of the patients interviewed had no loss of sensation in their hands or feet and

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had not experienced any problem attributable to sensory loss.

Forty-seven of those interviewed first discovered they had lost sensation by experiencing an injury which they did not feel. Eleven of these people did not know they had been injured until sometime afterward and could not remember how they had been injured.

Forty-one of the patients had never had any symptoms which would have indicated any problem with their sensory system. Twenty felt a numbness in their hands or feet during the time of losing their sensation. Nineteen said they had a feeling as if their hands or feet were covered, similar to wearing gloves, or a feeling that the insensitive part was swollen. Only four patients had any pain during the period of losing sensation.

The most common first injury was a burn on the hands. Thirty-nine of those interviewed stated that burns continue to be their most common injury. Only eight of these patients stated foot ulceration was their most common recurrent injury.

Sixty-four of those interviewed stated that injuries, which occur with no pain, left them feeling defenseless against injury, confused, afraid, and helpless. The others did not notice any changes in their well-being due to unfelt injury or the threat of it. Twenty-five had wounds which took a long time to heal. Eleven of them said they knew at the time that their continued use of the injured part was responsible for the delayed healing.

In order to protect themselves from further injuries, 42 of these patients had given up specific activities, including cooking, sewing, sports, walking, gardening, and other hobbies. Four had to quit smoking to keep from burning their hands.

Nineteen of those interviewed said they could not do delicate work, such as sewing, because of the loss of sensation. Seventeen had difficulty picking up or setting down objects, and all of the patients had trouble extracting things from their pockets.

Forty-nine of those interviewed stated that they were particularly careful during some activities such as cooking, gardening, and walking.

Twenty-two of them stated that they felt less close to their friends or family because they cannot feel to touch them. Sixteen of those interviewed stated that they would use

their hands or feet, even if it meant injuring themselves, to maintain or gain social acceptance.

DISCUSSION

Living with insensitivity can be frustrating, depressing, and lonely. Sensory deficit is not a problem which leaves a person feeling significantly different physically but, while doing the same things everyone else does, the person with sensory loss becomes injured and those with sensation do not. Healing an injury can take so long as to seem hopeless. A person with sensory loss has trouble setting objects down, picking objects up, and extracting objects from his pockets. He cannot feel when he touches things nor can he feel being touched by another person on an insensitive part of his body. These factors usually result in lower self-esteem for the patient, which can result in less concern for his own well-being.

When a person does not feel pain, there is no internal reinforcing mechanism to keep his attention focused on healing his open wound. The wound is not as personal to him; it can seem as though the injury is not on a part of his body and his insensitive limbs are seemingly expendable.

Treating a patient with insensitivity is not a hopeless endeavor. It does, however, require an understanding of the true problem created by sensory loss.

People with sensory loss, particularly in the hands and the feet, need mechanisms which provide an additional degree of protection and techniques of self-evaluation which can effectively provide a warning of impending injury. Many of these tests, such as daily skin temperature evaluation or visual examination, can become tedious or seemingly useless after a long period of negative findings. So, before any of these regimens can be instituted, the patient has to be convinced of the need for adding these inconveniences to his daily routine. Most of these programs are quickly discarded by patients who have never experienced severe problems, such as partial amputation. Injury without pain is not a personal experience.

Professionals treating patients with sensory loss should maintain an appreciation of the psychosocial impact of denervation. Some factors to be considered are: a) the

patient's participation in his treatment will be more passive than with one who has normal sensation. Therapies should rely less on patient compliance and should be aimed at restoring a sense of image and personal responsibility. b) The most common site of injury on an insensitive limb is the site of a previous wound (2). Careful monitoring during rehabilitation is needed to prevent reinjury to the same wound location. c) Supplemental techniques of diagnosis can assist in the detection of injury not perceived by pain. Other mechanisms of the body's response to injury, such as the inflammatory reaction, are intact and can be used to find the injury. Monitoring the skin temperature will reveal the presence of inflammation (8). d) With normal sensation, after the normal casting period for a fracture, a patient will continue to feel as though the injured limb cannot support full weight-bearing. This feeling is experienced because the fracture site has not completed the healing process. An insensitive patient can refracture these parts easily because he does not experience this lack of confidence in the injured limb after the cast has been removed. For this reason a patient with sensory loss should be casted for periods longer than normal, and needs to be closely monitored as he begins walking after the cast is removed. e) The professional treating an injury should emphasize to the insensitive patient that a wounded limb is still a part of his body, and that these wounds could result in systemic disease or loss of the limb. f) Many leprosy patients have lost sensation over much of the body's surface. During their physical evaluation, try to touch the patient on areas which still retain feeling. Their perception of this contact can have a significant therapeutic effect (6,7). Concern for their welfare can be conveyed by this method of communication (3).

SUMMARY

The psychosocial ramifications of the loss of sensation are subtle and often are not perceived. One hundred Hansen's disease patients were interviewed concerning their experiences of living with sensory loss on their hands and feet. Their responses to the questions may assist medical practitioners in the treatment of the effects of the disease.

RESUMEN

Las alteraciones psicosociales relacionadas con la pérdida de sensación, son sutiles y a menudo no perceptibles. En este estudio, se entrevistó a 100 pacientes con la enfermedad de Hansen en relación a sus experiencias de vivir con pérdida sensorial en sus pies y manos. Se concluyó que las respuestas de los pacientes a las preguntas planteadas pueden ayudar a los médicos o paramédicos en el tratamiento de los efectos de la enfermedad.

RÉSUMÉ

Les ramifications psychosociales de la perte de la sensibilité sont subtiles; souvent elles ne sont pas perçues. On a questionné 100 malades atteints de la maladie de Hansen, sur la manière dont ils percevaient la perte de sensation au niveau des mains et des pieds. Les réponses qu'ils ont fournies à ces questions peuvent aider les professionnels de la santé pour traiter les effets de la maladie.

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