

Phantom pain: A lesson in the necessity for careful clinical research on chronic pain problems

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Summary

Recent findings suggest that major misunderstandings concerning the prevalence, characteristics, etiology, and treatment effectiveness of phantom pain have led to the widespread mismanagement of amputees throughout the history of modern medicine. For years it has been believed that phantom pain is relatively rare, is of unknown etiology, and probably has a psychological basis.

Research results over the last few years, however, suggest that phantom pain is widely prevalent among individuals with amputations and most likely has a physiological basis. Although many different treatments have been introduced recently, few, if any, have yet been documented as effective due to lack of rigorous follow-up studies.

Future progress in clinical treatment and increased scientific understanding of phantom pain will require an examination of some of the factors that have led to past confusion regarding scientific research on and clinical treatment of phantom pain.

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The Myth

For years it was thought that phantom pain is rare among individuals with amputations (1) and, when occurring, is most likely of psychological origin (3).

The Reality

Recent surveys show that phantom pain is far more prevalent than previously thought. For example, we conducted a series of surveys of over 11,000 amputee veterans (12,15) which showed that experiencing phantom pain is the norm rather than the exception. Over 80 percent of respondents reported significant phantom pain. Other researchers have recently confirmed similar rates of occurrence in other populations (2,6,16).

Current evidence demonstrates that chronic phantom pain is usually a series of complex types of referred pain with very real physiological causes (8,10). There is no convincing evidence that a greater proportion of amputees reporting chronic phantom pain are psychologically abnormal or have abnormal personalities than the proportion of psychologically abnormal people found in the general population after adjustment is made for the effects of intractable chronic pain upon patients, their clinicians, and test instruments (13).

Treatment Dynamics that Perpetuate the Myth

The discrepancy between the long held myth of the rarity of phantom pain and the reality of its

high prevalence has led to treatment anomalies. These anomalies help explain why the myth was able to continue unchallenged until recently.

In one of our surveys of veterans with amputations, respondents told us their physicians had, early in treatment, directly stated or clearly implied that the pain they felt was "just in their heads." The great majority of amputees responding to this survey were afraid to inform their physicians that they were continuing to suffer with phantom pain for fear that the physician would think them insane. They were afraid to jeopardize the critically important relationship with their physician or risk losing credibility in reporting stump problems at a stage when verbal report is likely to be the only evidence that problems exist. Stump problems are frequently painful and can entirely prevent the use of a prosthesis for extended periods of time unless intervention is begun prior to development of obvious skin breakdown and other highly noticeable effects.

Because most patients were afraid to persist in their reports of phantom pain, physicians were only rarely confronted with patients who would report chronic phantom pain. In such cases, doctors would try to diagnose physiological causes, prescribe a series of treatment regimes until the patient stopped complaining or dropped from the caseload, or refer the patient for psychiatric examination. The way in which these actions have been carried out has often unwittingly led to perpetuation of the myths surrounding phantom pain.

Diagnosis

In the search for physiological causes, both scientists and physicians have tried to isolate differences between patients reporting phantom pain and patients not reporting phantom pain. This is based upon the reasonable hypothesis that if other things are equal, the differences between the two groups might reveal, directly or indirectly, the causes of phantom pain. Causes attributed to identified differences could then be treated. Unfortunately, since members of the "control group" also experienced phantom pain but were afraid to report it, significant differences were not evident and therefore

could not provide a fruitful basis for research or treatment.

In those cases where patient complaints of chronic phantom pain persisted, physicians were compelled to provide treatment. As is frequently the case in chronic pain syndromes, if one looks hard enough one can find something in the body which at least appears to be out of the ordinary. For phantom pain, the answer was abnormalities in the stump such as formation of neuromas. The logic is that if the patient reports pain, there must be something physically wrong with the stump, the nerves or blood vessels related to the stump, or the peripheral or central nervous systems.

Medical/Surgical Treatments

A wide array of medical and surgical treatments have been applied to those few amputees requesting treatment for phantom limb pain. We analyzed the world literature on treatment of phantom pain (9) and found that 43 unrelated treatments have been reported to be in recent use. They range from such drastic measures as lobotomies, through spinal surgery and reamputation, to more innocuous treatments such as injection of the stump with anesthetics and relaxation training.

We sent surveys to virtually all groups and hospitals in the United States whom we could identify as being likely to treat amputees. This included all VA hospitals, all medical schools, all pain centers, and all members of the International Association for the Study of Pain (14). The respondents identified 50 treatments in wide, current use. When the results of the survey and literature analysis were combined, a total of 68 treatments were identified. Almost none of the respondents carried out any follow-ups beyond a month and there were only a few 6-month follow-ups. Every treatment reported by practitioners as being successful was reported by others as being identified in their patient's records as unsuccessful.

In an effort to delineate treatment effectiveness, we sent surveys to 10,000 randomly selected veteran amputees (15), all 1,200 members of a national amputee veterans group (12), and over 500 self-

selected amputees whose amputations were of civilian origin (11). Only two percent of the respondents reported significant benefits from the host of treatments attempted (1.7 percent major permanent reduction in pain and 0.4 percent cure). The above surveys of both clinicians and patients indicated that there was no relationship between the treatment applied and the symptoms of phantom pain reported. There was no way to predict from symptoms or histories why those few patients who received at least some benefit from a particular treatment reported more success than apparently similar patients receiving apparently very similar treatments. The lack of any relationship between treatment success and any other variables, such as medical specialty, symptoms, etc., leads us to feel that these are randomly applied, useless treatments.

Thus, the widespread failure to carry out follow-up evaluations resulted in the practitioners being unaware that their treatments were usually ineffective when the criterion of continued significant reduction of pain at 1 year was used. The realities of current medical practice in the United States make doing appropriate follow-ups exceedingly difficult. If a patient is either unsatisfied or cured he will probably not come back, so the practitioner really has no way of knowing the actual results of the treatment for a large proportion of cases.

Psychiatric/Behavioral Treatments

When no differences can be identified or a long series of treatments do not work, psychological problems tend to be assumed for patients persistent enough to continue complaining of pain. Thus, a very skewed population of chronic pain patients are referred to the behavioral clinician. They consist largely of patients with whom the referring clinician does not get along and who persist in complaining about their pain through numerous interventions (4,5,13,17). We and other researchers have shown that these patients are characterized by persistence, rigidity, and unwillingness to say what the clinician wants to hear (7,10). In other words, they are people who tell the clinician when the treatment did not work, instead of just trying another clinician or

giving up. There is no evidence that patients reporting phantom pain are psychologically different from patients having other chronic pain syndromes or that phantom pain is frequently caused by psychological problems (13). It is exacerbated by psychological problems and stress in the same ways other chronic pain syndromes are (13).

Conclusions

Over the last decade of research with a variety of chronic pain conditions, including low back pain, subluxation of the patella, phantom limb pain, phantom body pain, and tension headaches, we have gradually come to the realization that careful studies are rarely carried out before new treatments for chronic pain syndromes are introduced into clinical practice. All too frequently, little time is spent actually attempting to define the physiological characteristics, subclasses, and underlying mechanisms of the problems. The result often is that clinicians from different specialties use their specialized clinical training and limited experience with treatments based on exposure to a restricted variety of patients to develop treatments based on their best, unsubstantiated guess about what the underlying problem might be. If the treatment appears to at least temporarily ameliorate the problem in a few patients, the method is often published without waiting for a follow-up period. This is a critical problem because about one-third of pain problems have been found to be amenable to placebo effects which can last for over a year.

Since follow-ups are rarely done, practitioners skimming clinical journals are left with the impression that the disorder is amenable to treatment with the published method. Because few specialists read outside of their own areas of expertise, there is little likelihood that they will be familiar with the plethora of unproven treatments that develop outside of their own field. The same pain problem is frequently reported as being successfully treated by a wide variety of interventions which have no common basis for efficacy. It may be years until publication of major clinical reviews indicate which of the many disorders the technique is used for is ac-

tually affected. This traditional method of developing treatments for chronic pain is clearly ineffective because most patients who develop chronic pain fail to receive treatments that result in significant relief.

It is imperative that research efforts ranging from deciphering of basic mechanisms through follow-up evaluations of treatment receive high priority support. It is also important for journals to clearly

identify those articles reporting the results of trial treatments with small groups or follow-ups of less than a year as being far less definitive than reports of blind, controlled, long-term studies. The expanded use of "clinical reports" sections in which these trials could be placed would be highly appropriate and could save considerable suffering for many people.

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