Letters

Correspondance

Diagnosis of fibromyalgia

Michael Puttick noted that a diagnosis of fibromyalgia can be made if multiple tender points are present.[1] According to the American College of Rheumatology, this condition can be diagnosed even if only 6 tender points are present, provided there is "moderate or greater tenderness."[2] I wish to point out that even if there is only one tender point in one of the typical areas for fibromyalgia, the pain in the tender point can be relieved by massage so dramatically as to confirm the diagnosis.

For example, there may be occipital pain, perhaps radiating over the skull to the frontal area, giving the patient the impression that she or he suffers from migraine. One feels a fibrous band in the muscle attachment in the occipital area, which softens on being massaged. Likewise, there may be only one painful point in the supraspinatus, but when one massages the area one senses a sort of bubbling or crackling under the thumb or palm, and with this the patient's pain begins to subside. The relief may be complete if the treatment begins soon after the onset of the pain but only gradual if the pain has been present for several days. The plasma myoglobin concentration has been shown to increase after massage for myofascial pain,[3,4] and the degree of tension and pain in the muscle is positively correlated with the plasma myoglobin level after the muscle is massaged.[4]

However, physician be warned. Treatment by massage is extremely painful; patients find it difficult not to shrink away from the pressure. Yet because the relief is so dramatic, they withstand the pain for the few minutes necessary and usually return when the pain recurs, perhaps after several weeks or months, to receive the treatment again.

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The community's voice in research

We congratulate *CMAJ* for inviting representatives from an Aboriginal community to put forward the community's reflections and recommendations on the basis of their experiences with a previous research project.[1] The Special Working Group of the Cree Regional Child and Family Services Committee wrote an eloquent commentary outlining how research can be strengthened through knowledge of community history and traditions and by incorporating local expertise and previous experience; they also stressed the importance of the local language and family or group decision-making. They proposed that researchers undertake intensive community consultations with health and social service personnel before undertaking research projects. In return, health care workers would need to recognize that their responsibilities include such consultations.

As a group with expertise in community-based research whose members include both Aboriginal representatives and researchers, we encourage the use of community-based participatory research. We developed a document that was accepted as a policy statement by the North American Primary Care Research Group to promote this method of research.[2,3] Community-based participatory research promotes the development of researcher–community partnerships. As a team the researchers and community representatives design the research (i.e., identify the nature of the problem, develop the most appropriate intervention and identify the best ways to assess the impact of the intervention), implement the intervention and evaluation, analyze and interpret the data and disseminate the results. In addition, it is our experience that these partnerships are greatly strengthened by jointly negotiated written ethical guidelines that outline the obligations of all team members and that promote sharing of decision-making and power. These guidelines help to maximize community knowledge and capacity building and to sustain programs after the funding for the project ends, which are the ultimate goals of all community-based health research.

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[One of the authors responds:]

The Cree commentary demonstrates that local people living in remote northern communities are comfortable with and interested in responding critically to an academic paper about a study that involved them.[1] Although not common in the literature, field-level responses to professional research will have an impact on research validity and are accessible to other potential participants in medical research because they are written in nontechnical language and in the first person.

The gestational diabetes project[2–5] marked an important stage in the evolution of participatory research practices in the Cree region. In the early 1990s, the Cree Board of Health and Social Services of James Bay sponsored research on gestational diabetes in the region. The resulting project became a partnership involving the Board, 4 communities and a university-based research team. The partners carried out community consultations during the planning phase of the project, hired local assistants, reported extensively to the communities during and after the project (in person, on radio and through popular language written reports) and provided the services of 2 nutritionists to the communities; the project also produced unanticipated spin-off research projects. The Cree commentary is a retrospective response by the community partners to the intervention aspects of the project.

Some things are obvious in hindsight. Today, a project like this would be planned through a research agreement based on the Board's code of research ethics and research guidelines. However, these tools have been formalized only recently, as part of the evolution of the partnership between the Cree and research communities. The gestational diabetes project has been a catalyst in this evolution.

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