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The Fibromyalgia Story: Medical Authority & Women's Worlds of Pain

by Kristin K Barker

Review by Anna Luise Kirkengen, MD, PhD

The sociologist, Kristin K Barker, scrutinizes the medical making of a disease: fibromyalgia syndrome (FMS)—a disease of painfulness, predominantly in women. She outlines the following: In the beginning is the story of the pain named “fibrositis.” After much research, this story ends with the dismantling of the misnomer: no inflamed fibers can be demonstrated to justify the diagnostic term.

Next comes the story of the tender trigger points—painful areas mapped on the body and “objectified” by means of a pain response to a certain thumb pressure exercised by the physician in a systematic way. Description of a pain experience is subjective and thus invalid. The response to a grip evoking pain, however, is considered objective, and therefore valid.

Despite the fact—and general acknowledgment—that pain is a subjective phenomenon, thumb pressure gains instrumental status for “transforming” a reported pain into a proven pain, rendering the pain an objective entity that can be dealt with as if not subjective (though it is). Thus, it is real. *Real* pain is proof of a *real* disease, defined as in the realm of rheumatology, although no inflammatory or autoimmune origin of the pain has been demonstrated.

In a critical analytical reading, the making of FMS is grounded in this scientific flaw, a fact that remains unacknowledged by the research community. Instead, the localization of the tender points, and the number of points needed to establish the diagnosis FMS, soon become central topics in a heated debate.

By 1990, the American College of Rheumatology (ACR) had to admit that FMS is to be considered an ill-defined diagnosis, at best. Barker delineates consistently why a large trial initiated and controlled by ACR can only be characterized as nonscientific: it rests on the flaw of the tender points; they both define and substantiate the “diagnosis.” Thus, all studies represent tautologies.

The amount of pain “out there” is so huge that it represents an appeal to what Barker calls “medical entrepreneurship.” Within the next decade, a stunning increase of FMS publications was observed. Between two dominating and polarized camps defining the condition as organic and psychogenic/behavioral, respectively, there are the “bridge-builders” of psychosomatics, and the advocates of a “bio-psycho-social” model.

By 2000, the uncomfortable question arising from a considerable body of nonconclusive research is: How is medicine to understand that, in a huge number of individuals, *all* perceptions translate into pain and *every* pain perception is exaggerated? Barker proposes two possible answers: “We do not know at all,” and “Our methods are not adequate.”

However, research continues “as usual,” documenting an “overlap” with a variety of other diagnoses—so-called comorbidities. People “in pain” are obviously also otherwise “in trouble.” The two main camps sophisticate their profile by focusing on complexities: a dysregulation spectrum syndrome versus affective spectrum syndrome.

It becomes ever more obvious that FMS research is no success story and investigations decline dramatically. Although a rheumatologic disease by definition, and by far the most common of disorders seen by rheumatologists, by 2005 fewer than 1% of specialist studies were on FMS.

Without comment from the side of the specialists, FMS has shown to be a predominantly female complaint. Although only a minority of publications explicitly addresses gender, most studies document a significant gender asymmetry. In addition to the conceptual flaws, the research community dismantles itself as highly gender-biased. FMS is inscribed by scientific measures into a long history of feminization of diseases from hysteria to neurasthenia to chronic fatigue and to chronic pain.

This methodological concealment of the gender bias in FMS-research is anchored in the biologic body, a body void of meaning and experience. Expressions of women’s distress are not seen and explored in a sociocultural context but biologized and medicalized. The colonization of female bodies by biomedicine has found a new realm.

Barker refers to phenomenologists, anthropologists, and sociologists who urge biomedicine to broaden its theoretic framework and methodologic repertoire. She advocates that medicine transcend its horizon from the biologic body to the body as embodied life. In doing so, clinicians and physicians will enable themselves to make meaning out of their patients’ lived experiences, and perhaps their own.

This is a really good book about why biomedicine is not good enough when judged according to its most noble mandate: to alleviate human suffering. ❖

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