Work Disability Evaluation and the Fibromyalgia Syndrome

Kevin P. White, Manfred Harth, and Robert W. Teasell

Fibromyalgia syndrome (FMS) is a common and costly cause of work disability. Patients with FMS, nevertheless, encounter considerable difficulties in their assessment of claims for disability payments. Factors that contribute to FMS as an important cause of disability are its high prevalence, the patients' perception of severe discomfort, and poor function. Disability evaluation in FMS is controversial for several reasons including lack of acceptance of the diagnosis, concurrent psychological abnormalities, difficulties in objectifying disability, deficiencies in instruments of evaluation, the uncertain efficacy of treatment, and physician attitudes. Third parties appear to have inappropriate expectations of the physician's role in determining disability. We suggest that the process of disability evaluation be improved by more objective assessments and by the inclusion of other health professionals in assessing disability and necessary retraining. Further research is needed to develop better instruments for measuring disability, to assess the long-term effects of various treatments, and to clarify the contributions of the work place and of compensation in causing or aggravating FMS.

INDEX WORDS: Fibromyalgia; disability evaluation; employment.

Patients with the fibromyalgia syndrome (FMS) may develop disability that is often considered severe enough to prevent them from seeking, continuing, or resuming gainful employment. Evidence for this comes from several sources and countries. A US survey of 620 patients with FMS showed that 15% were receiving disability payments; in a Swedish study of 55 patients with FMS, 24% had pensions; a British study of 72 patients, over a mean interval of 4 years, found that 50% had stopped working as a result of their illness. Data from a Canadian insurance company showed that FMS was responsible for 9% of all disability payments; the overall cost, to private insurers, of long-term disability due to FMS in Canada was estimated to be $200,000,000 per year. In Norway, in 1988, FMS was the most frequent single diagnosis for disability pensions. Despite, or because of this, patients with FMS appear to encounter
considerable difficulties in the assessment of claims for disability payments. Our objectives in this article are, first, to define the problems and controversies related to disability in FMS, and second, to propose suggestions for changes in evaluation and for further research designed to address these complex issues.

DEFINITIONS: DISEASE, IMPAIRMENT, DISABILITY, AND HANDICAP

The World Health Organization (WHO) differentiates between impairment and disability. Furthermore, both must be distinguished from disease. Disease has been defined as “any deviation from or interruption of the normal structure or function of any part of the body that is manifested by a characteristic set of symptoms and signs and whose etiology, pathology and prognosis may be known or unknown.” Impairment by the WHO definition is a loss or abnormality of psychological, physiologic, or anatomic structure or function; these disturbances are at the organ or system level, such as problems with hearing, vision, or specific musculoskeletal movements. An assessment of impairment is frequently what is sought in examinations performed at the request of determining agencies. In contrast, disability is “any restriction or lack . . . of ability to perform an activity in the manner or within the range considered normal for a human being.” A wider definition of disability is “an inability or limitation in performing socially defined roles and tasks expected of an individual within a sociocultural and physical environment.” “Impairment is concerned with discreet functions of parts of the body; disability is concerned with the performance of compound or integrated activities such as tasks, skills and behaviours.” Disability is a compound phenomenon that is determined not only by impairment but also by psychological, social, and economic factors. In the context of this report, we will use disability as synonymous with work disability (ie, an inability to engage in gainful employment).

Impairment and disability may result in a handicap (ie, a disadvantage that limits or prevents the fulfillment of a normal role). Employers may be understandably reluctant to hire or offer continuing employment to handicapped individuals.

Recognizing disability is least difficult where obvious disease and physical impairment exist, as in cases with limb loss, paralysis, or measurable loss of joint movement. Even then, it would be incorrect to assume that the degree of disease and impairment alone predict disability. For example, the loss of a limb might cause relatively minor occupational disability to a radio announcer, whereas even partial paralysis of a finger could be career ending for a concert pianist. Also, to borrow Jennings’ examples, it is possible to have disease without disability as with silent hypertension, and disability without disease, as with a reactive depression.

THE SETTING OF FMS DISABILITY CLAIMS

Claims for work disability can arise in several ways and involve various parties. A person with FMS may feel that the condition is severe enough to prevent continuing gainful employment and may claim payment for disability from a public agency such as the Canada Pension Plan or the plans managed by the United States Social Security Administration (SSA). If covered by a private disability insurance plan, the worker may alternatively claim for this or may make claims to both private and public insurers. If workers believe that FMS has arisen because of a mishap at work or as a result of the nature of their work, Worker’s Compensation may be requested. If FMS is attributed to a motor vehicle accident, workers may request compensation either from their insurer or from the offending party’s insurer. In any of these settings, the insurer, either private or public, will wish to evaluate these claims. Patients’ employers may also become involved, either directly or indirectly; the patient and/or the insuring third party may request special considerations in returning to work, such as changes in the work environment, reassignment to a different type of work, or reduction in the time of work. Under these circumstances, disagreements between the patient and other parties may occur with the possibilities of misunderstanding, conflict, and litigation. There are, in FMS, a number of factors that complicate and exacerbate these issues.
THE MAGNITUDE OF THE PROBLEM

FMS is relatively common, being one of the most frequently seen disorders in outpatient rheumatology clinics; it accounts for an estimated 2% of patients seen in primary practice, and 5% in a general medical outpatient population. Community surveys have estimated its general prevalence to be 0.66% to 3.2%. Its onset is predominantly in young adulthood or middle age, and women are much more often affected than men. Subjects with FMS have reported disabilities in activities of daily living that are as high as those for rheumatoid arthritis (RA), and higher than osteoarthritis (OA). Patients with FMS have rated their quality of life as lower than patients with RA or OA (Table 1). In a large survey of patients with RA, OA, systemic lupus erythematosus (SLE), scleroderma, and FMS, the latter reported the poorest global self assessment of functional status, the highest visual analogue pain scale, and the lowest global self assessment of health status. Patients with FMS have an increased perception of pain and fatigue (Table 1). Sleep disturbances are common. Memory disturbances and difficulties in concentrating have also been noted. Comorbidity with migraine and irritable bowel syndrome is high. Additionally, patients with FMS show below average aerobic fitness.

Several studies have pointed out that the condition tends to be chronic, with little improvement or even worsening over periods of 1 to 4 years. A more optimistic picture was presented in a recent Australian study of FMS patients who were not on compensation; in this group, improvement occurred over 2 years to the extent that almost half the patients no longer fulfilled criteria for FMS at the end of that time. FMS seen in rheumatology clinics may be symptomatically more severe than that seen in general medical practice or in the community.

Patients who have "reactive fibromyalgia," that is FMS following trauma, surgery, or a medical illness, may have an especially poor outcome, with one study documenting loss of employment in 70% and disability compensation in 34%.

Table 1: Contributing Factors to FMS as an Important Cause of Disability

<table>
<thead>
<tr>
<th>High prevalence of FMS</th>
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<td>High patient perception of discomfort</td>
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<td>Low self-assessment of function and health status</td>
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<td>Fatigue</td>
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<td>Impaired memory and concentration</td>
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<td>Frequent association with migraine and irritable bowel syndrome</td>
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Table 2: Controversial Aspects of Disability Evaluation in FMS

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<th>Debates On Acceptance</th>
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<td>Fibrositis, the name previously given to FMS, has been known for almost a century; it is only in the last two decades, however, that FMS has received recognition as a distinct, definable entity with clearly outlined classification criteria. Acceptance, however, is neither universal nor firm. It has been labeled &quot;an illusory entity&quot; and a &quot;medicalization of the syndrome of being out of sorts.&quot; One physician trying to explain to a patient what is wrong with her expresses his uncertainty as follows: &quot;... we really don't understand why it happens but we named it anyway ... fibromyalgia.&quot; Those who question the validity of the concept of FMS point out that its etiology and pathogenesis are unknown, that patients may appear well, that there is no objective evidence of joint or soft tissue disease, and that the usual laboratory examinations and radiographic and electrodiagnostic studies are either normal or nonspecific (Table 2). Despite muscle tenderness, muscle biopsy specimens have failed to reveal...</td>
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any consistent histological abnormalities. The only consistently reproducible physical finding is the presence of characteristically distributed tender points specified by the American College of Rheumatology (ACR); even this is still greeted with disbelief.

Although the diagnosis of FMS may appear somewhat tenuous, it should be noted that the classification criteria proposed by a committee of the ACR had a sensitivity of 88% and a specificity of 81% when FMS patients were compared with those with other musculoskeletal diseases. These figures are not much worse than those of the American Rheumatism Association criteria for the classification of RA, which have a sensitivity of 94% and a specificity of 89%. There may be no specific histological or radiological abnormalities in FMS, but neither are there in other well-accepted entities such as trigeminal neuralgia. Furthermore, certain hormonal and other biochemical changes have been described in FMS such as abnormal diurnal variations of corticosteroid secretion and low somatomedin-C levels. The prevalence of FMS in hyperprolactinemia is significantly greater than that seen in control populations. Tryptophan levels are lower in plasma and 5-hydroxyindoleacetic acid levels are lower in cerebral spinal fluid. These abnormalities may not be specific for FMS but nevertheless indicate organic changes. They suggest neuroendocrine disturbances and abnormalities of serotonin regulation that may be related to the sleep disturbance and abnormal pain reactivity.

There is a significant increase in the prevalence of psychological disturbances in patients with FMS. Their extent, severity, and significance present a complex and emotive issue. Some physicians and some insurers may regard these abnormalities as strongly suggesting that FMS is a psychogenic illness, possibly related to a conversion reaction or to a somatoform disorder. Patients with FMS have been tested with such instruments as the Minnesota Multiphasic Personality Inventory (MMPI), the Basic Personality Inventory, and the Symptom-Check List-90 Revised Subscale; when compared with patients with RA or normal controls they had, as a group, significantly higher scores for anxiety, depression, hypochondriasis, and somatization. These findings have to be interpreted with caution. First, it has been pointed out that patients with chronic pain, no matter what the etiology, will score abnormally on a number of these tests when compared with healthy controls; the use of psychological instruments such as MMPI in chronic painful conditions may be fallacious, particularly in assessing patients in terms of hysteria, hypochondriasis, and depression. Second, the majority of patients with FMS did not show significant differences in these measurements compared with patients with RA.

Patients with FMS seem to have more life stress and report a higher degree of functional disability than can be detected during short term direct observation. However, in one study they showed the same amount of observed impairment as patients with RA or ankylosing spondylitis. Indeed, it is the impression of students of this condition, such as Bennett, that many FMS patients "try to ignore their pain and accomplish the same goals" they had before their condition appeared. The majority of patients with FMS do not have a psychiatric illness. Regardless of whether psychological disturbances precede the onset of symptoms of myalgia and fatigue, or whether they are a result, they contribute to disability and have to be treated accordingly.

**Appropriateness of Evaluations**

In routine examinations, physicians often fail to recognize functional disability in ambulatory patients, sometimes overstating it but more often underestimating it. This seems to occur particularly in musculoskeletal conditions where the interaction of functional limitations and work requirements are strong determinants affecting work outcome. Work disability assessments in the context of the United States Social Security Disability Insurance (SSDI), or the Supplemental Security Income (SSI) programs have been criticized as inappropriate; likely, similar criticisms could be leveled in other contexts of disability insurance assessments. Liang et al assessed the adequacy of the SSA disability evaluation in patients with RA, OA, and SLE; there were marked discrepancies between the SSA assessments and those of independent rheumatologists and observed work capacity evaluations. RA, OA, and SLE are
much better accepted entities than FMS, and have associated imaging and laboratory criteria of severity; however, Liang et al.75 pointed out that work capacities are more difficult to define for musculoskeletal disorders, that fatigue and lack of endurance are not addressed in criteria for disability, and that information provided by physicians may be inadequate. FMS is characterized by a decreased ability to sustain repetitive activity or other forms of chronic work load6 as a result of pain, fatigue, global debility, poor aerobic fitness, and loss of concentration and attention span. These features are often under-emphasized or not considered in work disability assessments.75,76 There are no validated instruments for measuring disability in FMS. The symptoms of pain and fatigue are difficult to measure objectively. Instruments such as the McGill Pain Questionnaire,77 the West Haven-Yale Multi-Dimensional Pain Inventory,78 and the Pain Experience Scale79 have been validated as measuring pain, but they do not attempt to correlate pain with ability to perform remunerative work. The American Medical Association “Guides to the Evaluation of Permanent Impairment” are widely used for disability assessments in the United States; they include a Pain Intensity-Frequency Grid, which could be useful in quantitating pain in FMS if validated for this condition.80 The correlation between pain and disability is fair at best.81 Unidimensional and multidimensional instruments to measure fatigue have been developed, but none has obtained widespread acceptance, and they quantify fatigue rather than correlate level of fatigue with inability to work.82

There are methods for measuring function such as the Health Assessment Questionnaire (HAQ)83 or the Arthritis Impact Measurement Scales (AIMS).84 They have been validated for activities of daily living such as self toileting and doing errands but they do not directly address work capacity.85 In addition, these instruments were designed and validated for certain types of arthritis such as RA rather than FMS. The Fibromyalgia Impact Questionnaire (FIQ) is the only scale that addresses function in FMS, but it mainly focuses on instrumental and other activities of daily living, rather than work capacity.86

In FMS, clinical measurements such as the number of tender points or the total myalgic score (TMS) have been suggested in assessing disability.6 Tender points are an inherent part of the classification criteria of FMS42 and may change with treatment.87 TMS, which is measured by applying a dolorimeter (a modified pressure gauge) over certain tender point sites, is less sensitive or insensitive to change as contrasted with pain questionnaires and patient global assessments.88-90 Neither tender points nor TMS have been validated as measurements of function or disability.

Determining disability in FMS is further complicated by the frequent coexistence of FMS with other musculoskeletal conditions such as OA,91 RA,92 and SLE.93

In the absence of validated methods for measuring work disability, it seems more appropriate to use a tailored work capacity assessment, such as that described by Rogers, to determine if a claimant is capable of returning to a specific work situation.94 These assessments comprise a series of work simulation tasks, observed and rated by a trained assessor, often an occupational therapist; the assessment may take several hours or several days.94 The use of such assessments in FMS should, however, be validated for precision, accuracy, and long-term predictive power. A high degree of employer cooperation is required because the work and the work environment may have to be modified depending on the applicant’s performance. For instance, in a survey of more than 300 self-diagnosed patients with FMS, the respondents singled out certain aspects of work that were particularly aggravating, eg, cold temperatures, excessive use of the computer and typing, prolonged sitting, prolonged standing and walking.95

Treatment and Its Effects on Disability

The effectiveness of treatment in mitigating disability is a critical factor in evaluating its potential duration. Various therapies used in patients with FMS have included nonsteroidal anti-inflammatory drugs, serotonin uptake inhibitors (amitriptyline, cyclobenzaprine), antidepressants (alprazolam), low impact aerobic exercise, hypnotherapy, and cognitive behavioural therapy.97-90,96-100 These have shown variable degrees of effectiveness in modifying pain per-
ception, tender points, TMS, fatigue, and quality of sleep. Published trials show only short-term effects.\textsuperscript{87-90,96-101} Patients with less severe illness or normal psychological profiles may respond much better than others.\textsuperscript{89,90} Few therapeutic trials have included measurements of function,\textsuperscript{102} and only one showed a change.\textsuperscript{103} Work disability itself has not yet been used as a primary outcome in any published trial.

\textit{Disability Evaluation and Disability Compensation as Aggravating Factors of Disability}

There is a substantial literature filled with controversy on whether medically labeling a condition, raising the possibility of compensation, or awarding it, will in their own right, cause, prolong, or aggravate disability. An eloquent case for the dangers of labeling has been made by Hadler in discussing “black lung disease” in the coal-mining areas of the United States.\textsuperscript{104} On the other hand, not labeling conditions is unlikely to be acceptable to claimants, physicians, insurers, the legal profession, or legislative bodies. We will discuss these complex issues as they relate to FMS.

The Copenhagen declaration, which recognized FMS as a distinct diagnostic entity,\textsuperscript{105} may have exacerbated fears that the label of FMS will cause iatrogenic illness and disability.\textsuperscript{90,106,107} The validation of FMS as a cause of disability might result in patients seeking disability status as a solution for economic difficulties, especially as job satisfaction and financial security diminish during times of economic recession.\textsuperscript{47} Classifying the patient as diseased may actually be promoting illness behavior, learned pain, and learned helplessness.\textsuperscript{108,109} It has been suggested that legislation making it more difficult to validate claims for certain conditions as a cause of disability can affect the prevalence and degree of disability.\textsuperscript{110} The example of such legislation in the state of Victoria, Australia, with respect to filing of claims for whiplash injury is presented as a model because the number of claims fell over a period of 3 years by two-thirds.\textsuperscript{111} The introduction of head restraints as standard accessories for most cars sold in Australia at about that time may have contributed as much as the new law.\textsuperscript{110} More importantly, the number of claims does not give any information on the prevalence and degree of disability of those who were injured but were discouraged from filing for compensation.

Labeling a condition does not necessarily mean that its worst features will occur. This is as true of fibromyalgia as it is of ischemic heart disease or Hodgkin’s lymphoma. The data, which suggest a bleak outlook for patients with FMS, are not necessarily representative because they are largely obtained from rheumatology clinics. If, however, FMS were to be a uniformly debilitating condition, then those afflicted by it should have the same legal and moral rights to disability compensation as patients with better accepted conditions such as severe asthma or severe inflammatory bowel disease.

One of the difficulties currently encountered by claimants with FMS is the ambivalent attitude of some insurers and physicians. Claimants are aware that there are physicians who accept FMS and physicians who are either skeptical of the diagnosis or unwilling to assign it a high disability rating. In our experience, many insurers vacillate between outright rejection, and grudging and delayed acceptance. This threatens to make disability evaluation an aggravating factor where the patient has to run through what Hadler has called the gauntlet of disability evaluation\textsuperscript{112} with repeated evaluations, conflicting opinions expressed by various physicians, and the complications of prolonged litigation.\textsuperscript{112} This is a prescription for reinforcement of illness behavior.\textsuperscript{74,111}

The question of whether compensation worsens disability has been argued for a long time in the pain literature which deals mostly with back pain, and has a number of methodological weaknesses. Little is known about the effects of compensation on FMS. One study of a small group of patients suggested that resolution of litigation does not greatly alleviate the symptoms of FMS or lead to re-entry into the work force.\textsuperscript{113}

\textit{FMS Arising in the Work Place}

It is unknown whether working conditions can cause FMS. The turbulent history of the repetition or repetitive strain injury (RSI) epidemic in Australia has left us with only partial answers. In the 1980’s an epidemic of RSI occurred among telephone and keyboard operators working for Telecom Australia.\textsuperscript{114-116} RSI
claims spread to other industries and resulted in substantial litigations and large expenses. It has been suggested, however, that there was a decline in cases predating those court decisions. Various factors were implicated as possible determinants of the epidemic, including job dissatisfaction, ergonomics associated with the use of newer technology in the workplace, media hype, trade union activity, lack of knowledge of FMS by primary physicians, extensive investigations, adversarial proceedings of litigation, and the multicultural nature of the country. None of these circumstances is unique to Australia, and similar epidemics could occur elsewhere. RSI differs from FMS in that the majority of RSI patients have regional rather than generalized pain. Unfortunately, it is unknown how many RSI patients satisfied the criteria for FMS and what the incidence of FMS was before and after the epidemic of RSI. RSI is the closest model to a large scale occurrence of FMS attributed to working conditions. To forestall its recurrence, a number of measures have been proposed, including the education of workers and the health professions and improved ergonomics in the workplace; none of these has been evaluated as to its usefulness. It should be noted that, if FMS is as common in the general population as it seems to be, one would expect a certain number of workers to develop FMS during their working life coincidentally, rather than because of their work environment.

Directive Return to Work and Work Hardening Programs

Some physicians advising on the treatment of patients with FMS take the approach that the patient should return to work as early as possible; if this cannot be done directly, a work hardening program may be put in place. This strategy is based on comparisons with the success of early mobilization of cases of whiplash injuries and even more so on the apparent success of treatment of low back pain. Return to work studies that are cited have included those that lack appropriate controls; more importantly, those patients did not have FMS, a condition that appears to be more debilitating than either a whiplash injury or low back pain. The patient with FMS who may have been instructed previously to pace herself, to relax, and to "listen to her body" finds herself suddenly confronted with contradictory directions. Hadler calls these programs Kafkaesque. At times they are also reminiscent of Samuel Butler's satire set in the fictitious country of Erewhon where "illness of any sort was considered... to be highly criminal and immoral," and "the treatment of all convicted invalids had been much more barbarous... for no physical remedy was provided, and prisoners were put to the severest labour."

The Physician's Role in Disability Determination: Limitations and Shortcomings

The inadequacies of the process of disability evaluation in FMS are highlighted by the type of information requested from physicians by various insurers. In the case of SSDI and SSI, inappropriate examinations have to be performed frequently. The situation does not improve when dealing with other agencies or private insurers. There is no standardization of forms. Some insurers ask for information on activities that require strength, stamina, and agility, eg, ability to lift or carry certain weights, work at heights, or crawl; these questions are appropriate for certain occupations only; the answers are unlikely to be the result of direct observation unless the physician has an adjoining gymnasium and work shop. Physicians are often assumed, usually incorrectly, to be familiar with specific job requirements and with vocational training.

Insurers may request physicians to answer other irrelevant questions. We have been asked for information with respect to skin fold tenderness on rolling between the fingers, reactive hyperemia over tender points, and the abolition of trigger points by injection of local anesthetic; it is uncertain what relation these findings have to a disability assessment. Some physician assessors ascribe significance to "control points" which, if tender, are weighted as evidence against the diagnosis of FMS. Although control points were mentioned by the ACR Committee on the classification of FMS, they were not regarded as exclusionary criteria; furthermore, it has been established that "control
"points" are more tender in patients with FMS than they are in healthy people. Medical attitudes towards patients with FMS may also influence the evaluation. Some physicians feel inadequate in dealing with patients with chronic pain. Clearly, physicians who do not accept FMS as a valid diagnosis should not be asked to evaluate such patients for disability.

Evaluators may also be perceived as having conflicts of interest. Some physicians may perceive themselves as patient advocates, others as gate keepers or economic guardians; neither can be regarded as disinterested. In some instances, patients may be allowed to choose at least one physician as an evaluator in private insurance cases it is insurers who choose, thus casting doubt on the fairness of the process.

**Suggestions for Improving the Process and for Further Research**

To summarize, the process of disability evaluation in FMS is replete with inadequacies and shows several improprieties. Similar problems may occur, mutatis mutandis, in evaluating other conditions. Although the process seems to be open to abuse against patients with FMS, it is also susceptible to the converse. Certainly, any government or private insurance system that is left at the mercy of believing everything that disability applicants tell them is at risk of financial ruin. There is sufficient knowledge of FMS available to insurers to request pertinent information to justify the diagnosis. We think that the potential dangers of labeling have been exaggerated; in any case, avoidance of a label by one physician is unlikely to preclude labeling (correctly or incorrectly) by another, and can only arouse distrust. Furthermore, diagnosis followed by explanation and reassurance may dispell the patient's fears that persisting pain is sinister and harmful. The assessment of work disability and the advisability of retraining patients with FMS cannot be left to physicians alone. Occupational therapists, vocational counselors, psychologists, and other health professionals also must be involved. This is particularly true of patients who would be eligible to re-enter the work force, given some encouragement and help. Disability evaluation should be thorough and timely; it must be perceived by patients as fair. Private insurers, in particular, should consider the possibility of establishing a registry of appropriate independent evaluators for whom evaluation does not present a conflict of interest. This registry could be set up with the advice of various professional organizations and consumer groups. The evaluators could be paid through an independent fund with an arm's length relation to the insurance industry.

Numerous questions remain to be answered by applying the principles of epidemiology and health care research. The natural history of FMS must be determined in the population at large, not only as it exists in patients from rheumatology clinics. Instruments to measure disability in the work place must be developed and validated. The long-term effects of various treatment programs must be assessed, particularly with relation to disability. The role of compensation in disability must be clarified in terms of its functional, emotional, and social aspects. Further research is also needed into the contribution, if any, of the work place towards causing or aggravating FMS.

We do not believe these suggestions to be unduly idealistic or extreme. We think that they constitute reasonable alternatives to unnecessary conflict, litigation, loss of time, expensive referrals to self appointed rehabilitation groups, unnecessary medical and surgical interventions, and the unhappiness and frustration of thousands of patients who are poorly served by current practices.

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