

Caring for Medically Unexplained Physical Symptoms after Toxic Environmental Exposures: Effects of Contested Causation

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Medically unexplained physical symptoms (MUPS) are persistent idiopathic symptoms that drive patients to seek medical care. MUPS syndromes include chronic fatigue syndrome, fibromyalgia syndrome, and multiple chemical sensitivities. When MUPS occur after an environmental exposure or injury, an adversarial social context that we call “contested causation” may ensue. Contested causation may occur publicly and involve media controversy, scientific disagreement, political debate, and legal struggles. This adversarial social context may diminish the effectiveness of the provider–patient relationship. Contested causation also may occur privately, when disagreement over the causes of MUPS takes place in the patient–provider context. These patient–provider disagreements over causation often occur because of the enigmatic nature of MUPS. We suggest that a context of contested causation may have serious negative effects on healthcare for individuals with MUPS. Context plays a larger role in MUPS care than it does for most medical care because of the uncertain nature of MUPS, the reliance of standard MUPS therapies on a potentially tenuous patient–provider partnership, and the clinical need to rely routinely on subjective MUPS assessments that often yield discordant patient and provider conclusions. Contested causation may erode patient–provider trust, test the provider’s self-assurance and capacity to share power with the patient, and raise problematic issues of compensation, reparation, and blame. These issues may distract patients and providers from therapeutic goals. In occupational and military settings, the adverse impact of contested causation on the patient–provider partnership may diminish therapeutic effectiveness to a greater degree than it does in other medical settings. Contested causation therefore raises questions regarding generalizability of standard therapies for MUPS and related syndromes to these settings. Future research is needed to learn whether intuitively sensible and evidence-based MUPS therapies benefit occupational and military medical patients who are afforded care in the context of contested causation. *Key words:* chronic fatigue syndrome, environmental, fibromyalgia, Gulf War syndrome, medically unexplained symptoms, military, multiple chemical sensitivity, occupational, somatoform, veterans. *Environ Health Perspect* 110(suppl 4):641–647 (2002).

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Unexplained Symptoms after Events of Public Health Concern

In the early days of industrialization, risks and hazards were evident to the senses—they could be smelt, touched, tasted or observed with the naked eye. In contrast, many of the major risks today largely escape perception. . . . These risks exist in scientific knowledge rather than everyday experience. — Sociologist Deborah Lupton [(1); p. 64]

Medically unexplained physical symptoms (MUPS) have been defined as physical symptoms that prompt the sufferer to seek healthcare but remain unexplained after an appropriate medical evaluation (2). MUPS are perceptual (a person feels symptoms), cognitive (the person experiencing symptoms decides they are either ominous or benign), and behavioral (e.g., if the person decides the symptoms are ominous, he or she usually seeks healthcare for them). Studies show that MUPS are nearly ubiquitous—conservative estimates suggest that a fourth to a third of physical symptoms in the general population and in primary care settings are medically unexplained (3,4).

Chronic fatigue syndrome (CFS), fibromyalgia syndrome (FMS), and multiple chemical sensitivities (MCS) are among a growing number of symptom syndromes acknowledged as medically unexplained (2,5–13). Several investigators have noted that these and other MUPS syndromes have overlapping phenomenology (7,8,12–15), pathophysiology (12), risk factors (7), predictors of outcome (7), and effective therapies (5,7,11). Most argue in various ways that these MUPS syndromes are heterogeneous groupings of symptoms that merge into a single diffuse construct with unclear clinical boundaries—MUPS (6,9). Even

though MUPS are unexplained, they are not trivial—they are consistently and strongly associated with impaired functioning, psychosocial distress, and treatable anxiety and depressive disorders (4,16,17).

Epidemiologic studies find that MUPS are so common that we should expect that they would occur after all events or exposures that affect any modest-sized group of people. When MUPS occur after significant events involving environmental exposures, particularly if they are noticeable and impressive, the affected individual often reflects back in search of causes and then links MUPS to these worrisome exposures. This occurs even when the best scientific evidence suggests that a causal relationship is unlikely. Some of the most poignant examples of this have occurred after military or wartime service (18). In the early to mid-1990s, for example, veterans of the Gulf War developed MUPS, leading to questions regarding the possible presence of a Gulf War syndrome due to hazardous battlefield exposures (19). After World War I, many returning veterans described chronic debilitating physical symptoms and attributed them to chemical exposures incurred during months of trench warfare (20). After the Vietnam War, hundreds of thousands of veterans sought evaluation for concerns related to Agent Orange (dioxin) exposure (21).

Other examples in military personnel have occurred outside the context of war. MUPS became a focus of concern following mandated military vaccinations in the United States and United Kingdom (22). MUPS were a concern among Canadian peacekeepers after duty in Croatia, and many linked their symptoms to ruddy soil they encountered at one encampment (23). Apprehension regarding the relationship between low-level depleted uranium exposures and a possible “Balkan War syndrome” recently received worldwide attention (24). In the 1980s Dutch peacekeepers in Cambodia developed

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MUPS that became known popularly as “jungle disease” (25).

MUPS after environmental exposures of civilian populations have demonstrated that this issue is larger than military service and war. Examples include the 1979 threat of nuclear accident at Three Mile Island near Harrisburg, Pennsylvania (26), industrial waste exposures at Love Canal in Niagara Falls, New York, in the 1970s (27), exposures to implanted silicone medical devices (28), and possible toxic exposures from a jetliner crash in a populated area of Amsterdam (29). After the 11 September 2001 terrorist attack on the World Trade Center in New York City, concerns of a “WTC syndrome” consisting of cough, indigestion, eye irritation, and other symptoms emerged (30). Follow-up among survivors of the October 2001 anthrax attacks in the United States have uncovered persistent MUPS among handlers of mail that was irradiated to eliminate possible anthrax spores (31,32).

We do not cite these examples in an effort to diminish the medical significance of corresponding environmental exposures. To the contrary, many if not most of these exposure events are known to involve harmful environmental toxins. Instead, in this article we describe how the contentious social context that often follows these exposures may adversely affect healthcare delivery for MUPS. Context has a greater opportunity to directly affect medical care for MUPS than it does for more readily diagnosed diseases. We will show that the impact may be greater because of the uncertain nature of MUPS, the reliance of standard MUPS therapies on a potentially tenuous patient–provider partnership, and the clinical need to rely routinely on subjective MUPS assessments, assessments that often yield discordant patient and provider conclusions about patient health status.

Social Context, Contested Causation, and Unexplained Symptoms

In the quotation opening this article, Lupton (1) suggests that today’s major environmental health threats are often imperceptible. MUPS are mysterious in that affected individuals perceive them, but objective evidence proving their existence is elusive. For those who experience MUPS, the symptoms are all too real, and patients with MUPS are generally impatient with anyone who doubts the veracity of their symptom reports. Perhaps, therefore, it is not surprising that patients with MUPS sometimes connect their symptoms to unseen environmental exposures.

Social context may adversely affect the health of patients with MUPS when toxic exposures with plausible health consequences become a matter of media attention, high-

profile scientific discussion, political debate, wide-ranging litigation, or doctor–patient disagreement. These relatively adversarial circumstances may be described as “contested causation.” Contested causation may adversely affect MUPS-related healthcare at both the public and private levels. Contested causation is public when it involves population-level stakeholder conflicts. This type of contested causation occurs when scientists publicly disagree over evidence supporting or refuting linkages between MUPS and environmental exposures of wide concern, when large-scale litigation such as class action suits focuses on issues of responsibility and blame for the health effects of environmental exposures, or when political debate involves rancor between polarized adversaries. In publicly contested causation, the popular media often play a large role in disseminating the details of adversarial discussions.

Contested causation is private when patient–provider disagreements regarding cause occur because of the inscrutable nature of MUPS. An extensive literature suggests that in the absence of associated findings on physical examination or clinical testing, providers frequently conclude that MUPS are “minor” and less compelling than when they occur in association with an identifiable disease. In the privacy of the patient–provider relationship, the provider may reject or even directly dispute the patient’s beliefs regarding causation (33). Many providers view MUPS as manifestations of an underlying psychological problem, whereas most patients reporting MUPS find psychological explanations belittling. Different providers, especially those from different medical specialties, may vary widely in their conclusions regarding causation and treatment for a given patient with MUPS. Provider differences can add to patient confusion and possibly increase the likelihood of subsequent patient–provider diagnostic disagreements (34).

Our notion of privately contested causation is partly based on Hadler’s (35) description of an iatrogenic doctor–patient “contest” (as he noted, “It is hard, if not impossible, to get well if you have to prove that you are sick”) (35,36) Brown and colleagues’s (37–39) description of “popular epidemiology” has strongly influenced our conceptualization of publicly contested causation. Brown, a sociologist, described popular epidemiology as the manner in which lay members of environmentally “contaminated communities” (e.g., Love Canal, New York; Woburn, Massachusetts; and U.S. Gulf War veterans—the latter being a community joined by perception of a common experience rather than location) have organized to contest the “dominant epidemiologic paradigm” (i.e., empiricism and scientific authority).

Our concept of contested causation is also developed from Mazur’s (27) inventive use of the movie *Rashomon*, a 1950s depiction of an ancient Japanese fable, to illustrate how different stakeholders involved in Love Canal environmental exposure investigations eventually arrived at equally plausible but markedly different and adversarial perspectives of the same events and studies.

Dembe (40), a sociologist and occupational health services researcher, has performed an extensive historical examination of the social factors determining how occupational illnesses are recognized. He found historical evidence for the impact of social context on the patient–provider relationship, particularly for illnesses involving multifactorial pathogenesis. Dembe pointed out that for illnesses occurring via complex or poorly understood causal pathways, a clinical determination of occupational relatedness is less than straightforward. For example, some causal factors may reside inside but not outside the workplace, other causal factors may reside outside but not inside the workplace, and still other causal factors reside both inside and outside the workplace (40).

The central thesis of this article is that in the context of contested causation, healthcare for MUPS may be adversely affected. These adverse effects of contested causation may manifest in any healthcare setting, are probably greater in occupational and military medical settings, and may affect whether the results of MUPS treatment research studies done in general treatment settings can be generalized to occupational or military settings.

Patients, Providers, MUPS Treatment, and Symptom-Related Disability

Alleviating discomfort due to symptoms has long been a central focus of Western medicine. Indeed, relatively few therapies in medicine are curative. Symptoms are a major source of disability among patients with MUPS and those with well-defined diseases (Figure 1) (41), and some have argued that rehabilitative therapies targeting symptom-related disability may provide a model for making systemwide improvements in general healthcare delivery.

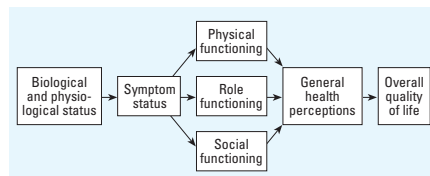


Figure 1. A causal model describing the relationship of biomedical (or disease) status and symptoms to functional status, perceived health, and overall quality of life. Modified from Wilson and Cleary (42).

As Figure 1 suggests, chronic symptoms from any cause (pain is the prototype) can lead to decreased health-related quality of life via at least three mechanisms: *a*) reduced tolerance for physical activity, *b*) distress and depressive and anxiety disorders that impair relationships and reduce social functioning, and *c*) diminished ability to fulfill key roles such as wage earner, spouse, or parent because of decrements in physical and mental health functioning. These mechanisms compound one another, creating a cycle of decreasing functioning, increasing risk factors for poor health (e.g., obesity, hypertension, smoking, drinking, and loss of social supports), increasing incident disease, increasing symptoms, and even causing greater decrements in functioning. Our group has found that MUPS are associated with small but measurable elevations in mortality, even after controlling for a number of potentially confounding mental and substance use disorders (42).

Two rehabilitative therapies (interventions usually based on behavioral principles that are administered to improve functioning and reduce disability), graduated physical activity (GPA) and cognitive-behavioral therapy (CBT), are empirically supported approaches for MUPS and related syndromes (5,11,43–45). The finding to date that different MUPS syndromes respond to similar therapeutic strategies is consistent with the theoretical model presented in Figure 1 and suggests that MUPS after environmental exposures may be treated early using these modalities until more definitive biomedical approaches are identified scientifically. This rationale was used to select candidate therapies for evaluation in controlled trials involving Gulf War veterans with MUPS (10,46,47).

We now briefly review GPA and CBT and then turn to the centrality of the patient–provider relationship in these therapies.

Graduated Physical Activity

Physical activity has important physical and psychological impacts on health and well-being (48,49). Structured approaches to GPA improves outcomes for a wide range of illnesses such as chronic low back pain (50,51), depressive disorders (52), diabetes mellitus (53), multiple sclerosis (54), and even cancer patients in chemotherapy (55). Several studies of CFS and FMS have determined that GPA improves global symptoms, including pain (56–61). Reid et al. (44) noted that there is considerable indirect evidence suggesting that bed rest, the opposite of exercise, is harmful. GPA may improve symptoms and functioning by increasing strength, decreasing fatigue, and increasing endogenous opioids (62). Exercise can also improve well-being, sense of control, and mood (52,63,64).

Physical activity for MUPS requires a tailored, flexible, and graduated approach. Rapid introduction of strenuous exercise can exacerbate symptoms and reduce subsequent adherence to physical activity (65). Decisions regarding how and when to resume work are important, too. An early return to work generally serves to bolster role functioning and self-esteem. A supervised, graduated return to work-related activities is most necessary for jobs with physical conditioning standards. Rapid return to supervisory and other non-physical roles may offer patients opportunities for early success and reinforce co-worker expectations of a full recovery. In contrast, rapid return to strenuous job-related physical activities is discouraging and self-defeating for most patients.

Particularly in occupational and military healthcare settings, policies that support graduated levels of increasing responsibility and activity after injury or illness may improve rates of successful return to full occupational function. We would predict that a return-to-work policy based on the presence or absence of a disease is more likely to result in unrealistically rapid attempts at resuming physical functioning for MUPS and frequent failure to promote gradual increases in physical activity and role functioning in patients with diseases.

Cognitive-Behavioral Therapy

Most studies have found CBT to be effective for a wide range of MUPS, including FMS, CFS, and irritable bowel syndrome (11,66,67). CBT stems from the theory that symptoms and poor functioning occur

because of a complex integration of pathophysiology, cognition, affect, and behavior (68,69). The aim of CBT is 2-fold: *a*) to facilitate a safe and graduated improvement in functioning without exacerbating symptoms and *b*) to jointly examine problems and beliefs in an effort to negotiate solutions, identify and revise harmful beliefs, and adopt active coping strategies.

Common components of CBT are time-contingent activity pacing, pleasant activity scheduling, sleep hygiene, assertiveness skills, self-examination for harmful or negative thinking, and structured problem-solving skills. These strategies, alone or in combination, have been used successfully to improve functioning among patients with MUPS and other chronic illnesses (70–78).

Figures 2 and 3 summarize this short discussion of rehabilitative approaches to MUPS. Figure 2 explicates key causal pathways by which MUPS lead to reductions in health status. Pathways involving harmful health beliefs and health behaviors are prominent and lead to psychosocial distress and increasing disability. Figure 3 illustrates that CBT and GPA act on all four of these areas, leading to improvements in health status in individuals with MUPS.

The Patient–Provider Relationship in Successful MUPS Care

The success of GPA and CBT hinges on a cooperative patient–provider relationship. Any clinical intervention, of course, calls for providers to help patients change health behaviors. For example, even a simple

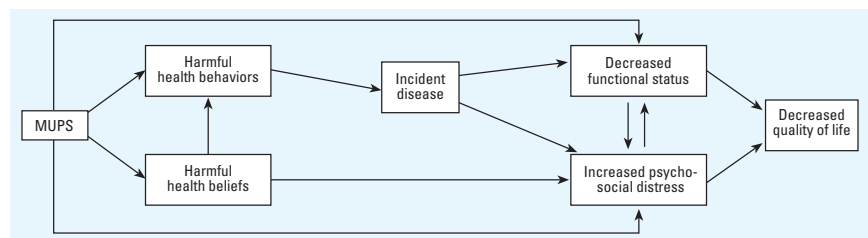


Figure 2. Causal pathways by which MUPS may lead to reduction in health status. Pathways involving harmful health beliefs and health behaviors are prominent and lead to psychosocial distress and increasing disability.

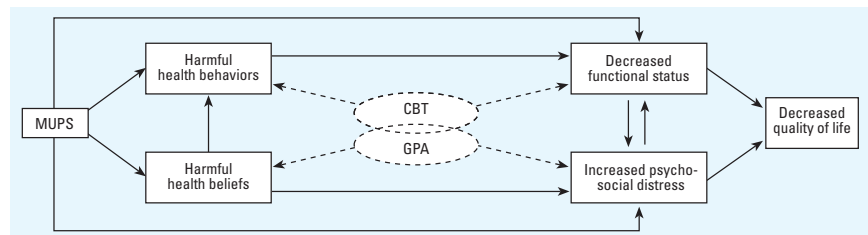


Figure 3. Mechanisms by which CBT and GPA mitigate the impact of harmful health behaviors, harmful beliefs, decreased functioning, and increased psychosocial distress on health status among people with MUPS (dashed lines represent mitigating effects of the therapies).

curative therapy such as an antibiotic for a minor infection requires the patient to adhere to a medication prescription. However, persuading a chronically ill patient to embark on a physical activity program or a patient with low back pain (often viewed by the patient as physical disease) to adhere to CBT (often viewed by the patient as “psychotherapy”) requires well-developed provider communication skills and a high level of patient and provider confidence in one another.

Von Korff et al. (79) define collaborative management of chronic illness as “care that strengthens and supports self-care in chronic illness while assuring that effective medical, preventive, and health maintenance interventions take place.” Key elements of collaborative management that they outline include *a*) collaborative provider–patient definition of problems; *b*) negotiated targeting, goal setting, and planning on the basis of both the importance of the problem and patient motivation and readiness for self-care; *c*) creating a continuum of self-management training and support services; and *d*) active, sustained follow-up. Components of collaborative self-management training such as GPA and CBT require joint patient–provider negotiations to define goals, priorities, and outcomes of interest. The provider must often inspire and support patients through extended behavioral change. This requires regular follow-up, demonstrations of ongoing provider commitment to the patient, regular reassessment of treatment goals, and joint problem identification and problem solving. Contested causation erodes the foundation for these efforts, the collaborative patient–provider partnership.

Contested Causation and MUPS Care in Occupational and Military Settings

Von Korff et al. recommended a system-level approach to enhancing collaborative care of chronic illness (79). Their recommendations were to *a*) implement performance indicators and incentives that motivate improved care; *b*) seek science-based technical assistance to disseminate research findings and effective programs; *c*) develop and implement practice guidelines and clinical information systems; and *d*) involve employers, community organizations, government, and patient advocacy organizations in efforts to improve care. Since 1994, the U.S. Department of Defense (DoD) healthcare system has pursued this approach to improve health services for MUPS and other postdeployment health concerns. That year, the DoD Comprehensive Clinical Evaluation Program, a diagnostic evaluation and clinical registry, was initiated to address MUPS and other health concerns among Gulf War veterans. In 1999, the DoD effort was expanded to include all

military-related health concerns and MUPS, and our group has been at the center of these efforts. At issue, however, is whether there is adequate evidence to conclude that a program of collaborative management for MUPS can succeed in occupational settings such as the military.

In 1995 the DoD established a multifaceted and interdisciplinary center providing rehabilitative care for military personnel reporting persistent and disabling MUPS after Gulf War service (47). The Deployment Health Clinical Center at Walter Reed Army Medical Center in Washington, DC, has since adapted GPA and CBT to the treatment needs of military personnel, veterans, and family members with MUPS (46,47). Pretreatment–post-treatment data from patients completing this 3-week referral program for MUPS show consistent, modest improvements in participants’ functioning, symptoms, physical health concerns, and psychological distress lasting at least 3 months after treatment (47).

In 1998 the U.S. Department of Veterans Affairs (VA) and the DoD co-sponsored a randomized controlled trial of GPA and CBT, and the study is nearing completion. This study, described in greater detail elsewhere (10), compares 1-year health outcomes for Gulf War veterans with MUPS after 12 weeks of either GPA, CBT, GPA and CBT, or usual care. Twenty sites and nearly 1,100 veterans have enrolled in the study, making it the largest study of GPA and CBT for MUPS to date and the first study to evaluate these strategies in the occupational healthcare setting (10).

In 1999 the DoD and VA decided to develop clinical practice guidelines integrating lessons learned since the Vietnam era regarding postdeployment healthcare. The DoD–VA *Clinical Practice Guideline on Post-Deployment Health Evaluation & Management* (80) and the VA–DoD *Clinical Practice Guideline for the Management of Medically Unexplained Symptoms: Chronic Pain and Fatigue* (5) are being implemented starting in 2002. Each of these guidelines has its own set of performance indicators to identify implementation successes and gaps. “Tools” (e.g., assessment measures, patient and provider education brochures and videotapes) have been developed facilitating the care prescribed in the guidelines. One guideline tool is the website “PDHealth.mil” (<http://www.pdhealth.mil>), which is open to the public and provides prompt information on the health effects associated with military-related hazards. Also posted on the site are news media articles that make providers aware of public information available to patients that might cause them to seek medical assistance. Goals of the site are to equip

clinicians with near-real-time health information and to foster openness between federal healthcare providers and concerned healthcare system beneficiaries.

In 1999, the Deployment Health Clinical Center became the DoD center of scientific expertise pertaining to postdeployment healthcare delivery. In addition to providing referral clinical services, the center runs continuing health education programs and health services research projects that aim to improve care for MUPS and other military-related health concerns. The center currently has health services research projects under way that are funded by the U.S. National Institutes of Health, the U.S. Centers for Disease Control and Prevention, the DoD, and the VA.

Scientifically valid research to evaluate the effectiveness of these comprehensive federal healthcare programs is a necessity given the concern that contested causation (and perhaps structural influences unique to the federal healthcare system) may subtly erode the provider–patient partnership over and above what occurs in the nonoccupational settings where previous MUPS treatment studies have been performed. Next we review possible mechanisms behind this putative erosion.

Threats to Collaborative Management Posed by Contested Causation

Lay people are aware of their dependency on expert knowledges when it comes to disputes about risk. They are also aware of their lack of agency and opportunity, as ‘non-experts’, to challenge expert knowledges, even if the expert knowledges are uncertain or conflicting. [(1); pp. 110–111]

What reasons exist to think that contested causation may adversely affect the care of MUPS? We have illustrated the centrality of the patient–provider relationship in standard MUPS therapies. Historical evidence exists, derived from careful accounts of work-related diseases, that social context can affect the patient–provider relationship, particularly in occupational settings (40). This may occur through any of several overlapping mechanisms:

- Contested causation may erode patient–provider trust, mutual respect, and confidence.
- Contested causation, when mixed with the inherent medical uncertainties surrounding MUPS, may test provider expertise and capacity to share power with affected patients.
- Contested causation, due to inevitable questions of compensation, reparation, and blame, may distract from usual therapeutic goals.

These mechanisms are not mutually exclusive, occur to some degree in all medical

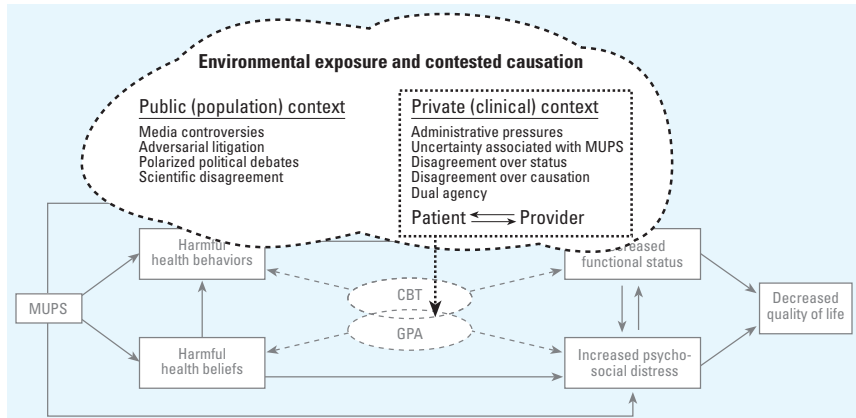


Figure 4. Contested causation reduces the efficacy of collaborative management of MUPS through erosion of the patient–provider relationship. Contested causation may affect care through private disagreements between patient and provider or through population-based effects resulting from contentious public discourse occurring after environmental exposures (dotted lines in the foreground represent contextual effects).

settings, and may have a greater impact in occupational or military healthcare settings. Figure 4 offers a visual model to show how contested causation may reduce the effectiveness of collaborative MUPS management.

Contested Causation and the Erosion of Trust

Uncertainty regarding the causation of MUPS provides greater opportunity for disparate patient and provider conclusions regarding legitimate causes. If a patient links his or her MUPS to a contested cause, appropriate provider skepticism may turn instead to overt mistrust of patient motives. Similarly, if a patient perceives (whether correctly or incorrectly) that providers have conflicts of interest that may interfere with their duty to afford them treatment, patient mistrust for those providers may result. For example, the patient may not trust an occupational physician employed by the workplace if the patient perceives that the physician is protecting the employer from liability rather than protecting the workers from medical risk or harm. Another strain on trust that occurs in all healthcare settings but is likely to be amplified in the occupational and military setting is patient fear that the provider may label them with a problem that will follow them in the workplace and endanger their career. MUPS after contested causation, therefore, sometimes create patient doubts regarding provider sincerity and expertise, and provider doubts about patient veracity and desire to pursue health improvements.

In the context of contested causation, other insidious sources of patient–provider mistrust may exist. For example, the field of environmental risk communication often teaches that mistrust among concerned parties is heightened in the presence of certain

affect-laden “fear factors” related to the characteristics of or circumstances surrounding suspected environmental exposures (81):

- Industrial or man-made exposures (vs. natural exposures)
- Mysterious or poorly understood health problems such as MUPS (vs. better understood diseases such as diabetes mellitus) (81)
- Real or patient–perceived conflicts of provider interest (82)
- Patient history of iatrogenic injury (33,83)

In the face of news media stories or high-profile political power struggles or legal wrangling, fear factors may contribute to an overtly adversarial provider–patient relationship. Adverse outcomes that result may include reduced patient adherence, increased provider frustration, or even mutual rejection (84).

Contested Causation, Provider Expertise, and Patient–Provider Power Sharing

Contested causation and its differential impact on patient and provider explanations for MUPS may create provider–patient conflict and reduce collaboration (85–87). An optimal patient–provider partnership occurs when the patient respects the provider’s medical expertise. Although attitudes are changing, providers remain generally used to relatively unchallenged clinical authority. When provider and patient views differ, however, patients may challenge or question provider opinions, provider skills, or even the provider’s claim to special expertise. For example, a patient may reject a provider’s expert opinion if it conflicts with personal experience (88,89). If a patient incorrectly concludes that a diagnosis of depression means that the provider believes the patient’s symptoms are imagined, the patient may reject the diagnosis and perhaps the provider

because the patient knows with certainty that the symptoms are valid (88). Regarding workplace illness or injury, the patient may feel better informed and more aware of the potential for environmental exposures than a provider who does not deal personally with these risks. These are arguably legitimate patient claims to personal knowledge, given that direct evidence in humans regarding the health effects of many low-dose environmental exposures is sparse, difficult to interpret, and subject to methodological uncertainties.

In the ideal patient–provider partnership, providers must share control of the therapeutic method and value patients’ knowledge of their symptoms. However, in the context of contested causation, these threats to the provider’s traditional role as medical expert and authority can trigger defensive provider responses. Providers may reject patients that challenge them, or they may invoke pathologizing formulations of patients’ personal manner as “difficult” and patients’ MUPS as “psychogenic” (87). In military and occupational settings, administrative pressures to reach parsimonious explanations for complex patient presentations may further amplify these effects.

Contested Causation May Distract from Therapeutic Goals

An effective patient–provider partnership requires both patients and providers to focus attention on improvement of patient functioning. Scientific controversy, political debate, and media attention accompanying contested causation may complicate patient and provider efforts to maintain a consistent focus on therapeutic goals. Often, debates surrounding contested causation implicate “victims” and “oppressors” or “winners” and “losers.” These public debates may distract both patient and provider from therapeutic goals and may affect provider and patient beliefs regarding fairness, entitlements, or need for disability compensation. These provider and patient perspectives may remain unspoken, yet they can still dominate the clinical encounter and distract from efforts to improve patient health (36).

Societal discourse around contested causation, responsibility, blame, and reparation may create predicaments for patients and providers. For example, patients may perceive that “getting well” will risk sending the message to observers that their illness or injury is trivial and therefore that compensation is unneeded. For providers, a common therapeutic goal involves encouraging patient improvements in health behavior and knowledge. However, when compensation is at issue, providers may instead feel more compelled to provide an exact biomedical accounting, even if doing so fails to offer

disease-specific therapeutic options. For example, providers may explain MUPS as conversion symptoms or a somatoform disorder even though it does not lead to specific therapies and may leave the patient feeling stigmatized.

Treatable and frequently undiagnosed depressive and anxiety disorders often accompany MUPS and compound disability (90). Diagnosing these problems, linking diagnoses to effective therapeutic options, and negotiating acceptable explanations and labels comprise appropriate care. Sometimes, however, contested causation may increase the tendency for providers to adopt psychological explanations for MUPS in an effort to reassure the patient. Patients experiencing MUPS, however, are seldom reassured and often outraged with such explanations. Patients may feel the provider has stolen hope for resolution by blaming them for their symptoms and then failing to offer acceptable treatment.

The other, equally unproductive extreme, may also create distraction. In the context of widely contested causation, the provider may embark on a “no-stone-unturned” search for a disease to explain the patient’s symptoms. Although recognizing the diagnostic yield to be diminishingly small, the provider–altruist may run the test anyway. Paradoxically, this approach may distract the provider and the patient from appropriate treatment. This occurs when the mystery, drama, and hope of the diagnostic process captivate patient and provider, leaving them spectating rather than participating in collaborative management. It may also lead to medically unnecessary patient risk.

A final form of distraction sometimes occurs when the provider believes that publicly contested environmental causation is unscientific, “political,” or frivolous. To prevent “over-utilization” of expensive medical resources in a manner that might nurture illegitimate medical fears, the provider may prematurely halt the process of care without fostering a patient–provider partnership and negotiating acceptable therapeutic options to reduce disability.

Summary and Conclusions

We have reviewed the notion of MUPS, the overlap of MUPS with several common but poorly understood symptom syndromes, and the predictable occurrence of MUPS after controversial community, occupational, and military exposures. We have asserted, based on an emerging sociologic literature on community exposures and occupational illnesses, that the adversarial social context that often accompanies these environmental exposures, a context we have referred to as “contested causation,” may have an adverse effect on the care of many individuals with MUPS. Factors

that allow social context to have a larger role in MUPS care than for many well-defined diseases are the uncertain nature of MUPS, the extensive reliance of standard MUPS therapies on a potentially tenuous patient–provider partnership, and the routine need to rely on subjective clinical assessments that are often interpreted differently by the patient than the provider.

Contested causation may adversely affect MUPS care in any medical setting, making it difficult to translate the efficacy of CBT and GPA found in clinical trials into routinely effective clinical practice. Even within a supportive healthcare system offering an array of collaborative patient management options, if causation of MUPS is contested publicly (e.g., in the news media) or privately (e.g., during an office visit), concerns regarding dual agency, veracity, and trust often arise and distract from the fundamental goal of improving patient quality of life.

Occupational and military medicine may be more vulnerable to these effects on MUPS care than are other medical systems. Federal medicine has embarked on an ambitious multipronged clinical and policy effort to address military-related MUPS. These efforts include referral programs, clinical practice guidelines, information dissemination strategies, and scientific and clinical centers of excellence. We are playing a central role in these efforts, and we think they are well placed given historical evidence suggesting escalating societal and patient concerns about enigmatic MUPS syndromes with potential environmental etiologies. The theoretical probability that contested causation poses additional threat to effective MUPS care in occupational or military settings means that we must demonstrate, wherever possible, the efficacy of MUPS care in these settings using carefully designed, scientifically valid, randomized controlled trials.

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