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## A Novel and Effective Treatment Modality for Medically Unexplained Symptoms

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### Abstract

Medically unexplained symptoms (MUS) confound physicians, and the incidence and prevalence of these conditions is poorly documented. This is not least due to the complex nature of MUS and mimicry of morbidity with conditions that have common clinical assessment and treatment modalities, e.g. migraine headaches which stress headaches commonly are misdiagnosed as. Effective treatment modalities for MUS have been more or less non-existent. In the following we present a modality for the assessment, diagnosis and treatment of MUS that in our experience leads to cure, at least in better than half of these cases measured in terms of allowing the individual back to work. These results are at least twice as high as those described hitherto (see below), and yet, our treatment modality is beset with many obstacles, not the least of which is the intransigence of a system that will not and/or can not understand why this modality is so much better than what they are able to offer. The most important obstacle is financing, as this modality requires long term and committed financing to work. The economic implications of not dealing with these issues are described.

**Keywords:** medically unexplained symptoms, back to work.

### Introduction

For decades authors have described, in varying levels of detail, classification, quantification and assessment of the economic impact of patients with medically unexplained symptoms (MUS) (1,2). The syndromes commonly presenting to clinicians lacking discernable and/or measurable, concrete symptoms include, but are no means limited to, whiplash syndrome, chronic fatigue syndrome, post-viral syndrome, chronic lower back pain, chronic stress headache, chronic muscle pain and various others. More recently a few studies have surfaced which assess various treatment modalities for this group, and

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the conclusion until now has been disappointing. In what we view as the best review of the area to date it is clearly stated that there is no effective treatment modality for this group (3-5). In all of the cited works, a commendable effort to adhere to the standardized approach to treatment evaluation is applied. We present a novel approach which departs significantly from previous attempts in five delineable areas, namely how the patients are triaged, where the treatment takes place, who delivers the treatment, how the treatment is individualized and what the dependent variable is for evaluation of the treatment. We have demonstrated that the described treatment modality can bring better than half of the patients treated from a generally painful and disabled state back to the workforce, and that the methodology of the modality is generalizable.

In dealing with MUS patients, it is imperative to dare to leave the world of the double blind, randomized and controlled trial (DBRCT) behind. This is predicated by the highly individual circumstances leading to MUS and the enormous variation in the response type to these circumstances. This variation is highly dependent on many personal psychological traits, perhaps the most important of which is resiliency, which is at best a difficultly quantifiable trait (6). Even in the best of the DBRCT world, the issue of patient variation and the lack of congruence between the standardized trial person and the real world use of the intervention and/or medication in question is problematical. The father of clinimetrics, the late Alvin Feinstein, discusses this problem at length in the seminal volume *Clinimetrics* (7,8). The issue is clearly evident to the practicing physician who is seldom able to directly correlate the patient model in the typical DBRCT trial to his/her daily round patients (if indeed he/she even attempts to assess this) nor is able to apply the conclusions drawn from the typical DBRCT directly to the practical clinical situation. In the typical MUS patient (given this term makes any sense at all given the above), these problems become all the more critical precisely because the issues leading to MUS are highly individual and therefore impossible to match. Further, the typical MUS patient would refuse to participate in a study that involved a treatment modality that for example tested the efficacy of delivering treatment locally versus her having to travel with her symptoms

to a centralized unit delivering the same service. Why would a chronic pain patient participate in a trial of this nature and risk having to go through many painful journeys when the expertise can be delivered locally? Further, why would a chronic pain patient expect a good result from a standardized approach when an individualized approach is offered? Taking this logic one step further, when it is obvious (to the patient, at least) that delivering this sort of treatment locally and individually tailored is better than a painful journey for the patient to and from a centralized unit to a standardized treatment, how would one defend allocating one patient to a local and individualized offer and thereby force the "match" to go through the normal pattern of a centralized unit? Further yet, if this treatment modality is so obviously superior to the centralized offer, what use is a study of any nature (excluding of course an evaluation of the efficacy)?

In the world of the stringent DBRCT the methodological issues often overshadow the item of study, i.e. statistical evaluations of survey tools or detailed descriptions of the matching and/or randomization process, but these issues are rarely candidly discussed by the authors in terms of issues of validity and reliability. This lack of self critical discussion is widely accepted in scientific journals, for which reason these have a decided tendency to favor DBRCT studies over treatises that call this practice into question (9). This so-called evidence based world will invariably miss the most important parts of the story behind MUS exactly because one can not put together a trial which standardizes the patient with psychological trauma and the individual responses thereto that fuel MUS (10) for the reasons just mentioned. The resistance to this argumentation which invariably will come forth from the DBRCT powers is not, we argue, a weakness in our reasoning, but rather a weakness in the DBRCT model. Let them show better results with this group, and we will let our arguments fall. This is discussed at greater length below.

## **Cochrane**

Review protocols by the internationally esteemed Cochrane Collaboration have traditionally emphasized the value of experimental designs in the

generation of evidence (11). However, as Sir Archibald Cochrane states himself as a key principle in his foundational work, evidence can only be generated with patients, not on patients. This principle is now increasingly recognized, the vanguard of a multi-methodological approach being led by the Cochrane Health Promotion and Public Health Field (12). This initiative emphasizes the necessity of gathering all kinds of evidence, not just the “hard” evidence gathered by the typical DBRCT comparing one medical intervention to the other, or against placebo.

The kind of thinking necessary here is how to create evidence that setting a broken bone is better than not setting it. This has never been the issue of a DBRCT, yet no one questions it. Designing a DBRCT for the purpose of finding whether setting a bone is effective would be highly nonsensical as well as unethical. The same kind of logic applies to the treatment modality presented here, and the same level of nonsense and unethicity applies to the issue of creating a trial that shows the difference.

This does not mean that anything goes, however. In our experience, quality and the fundability of a given treatment modality which can not be tested is dependent on clear outcome measures that make sense to all involved (e.g. setting a broken bone). In dealing with MUS patients, our outcome variable is back to work - short but sweet. We maintain that the re-engagement of the MUS patient in the work force is the strongest statement that can be made regarding the quality of the treatment modality. In our view, this output variable is just as strong as the healing of a broken bone. In addition to this dependent variable, certain basic elements of what constitutes a reasonable and fundable activity must be maintained (see below).

The economic impact of MUS is widely recognized as being enormous, and growing (13,14). The discourse around the socio-economic impact of MUS is, we maintain, nevertheless unfocused and often obscure. The most important issue in this context is that there is no standardized registration of this group as such, and how would one devise such a registration? As noted above, MUS patients are seen by various specialists because of symptoms that mimic commonly assessable and treatable disease entities (15). As long as the specialists in question

have yet to rule out the typical symptomology they are used to, the MUS patient remains undiagnosed. Meanwhile, MUS is not a recognized disease entity and there is no consensus as to what sort of specialist is relevant in these cases. For this reason among others, the majority of MUS patients are unseen by appropriate assessment experts. This compounds the difficulty in quantifying MUS. In Denmark, where this experience comes from, doctors are, mostly for the better, an integral cog in the bureaucracy of social welfare and health care, i.e. they play an important role in decisions regarding social welfare for unable and/or disabled individuals. The primary author has spent more than five years functioning as a medical consultant for a series of Danish communities. Approx. 10,000 sick leave patient dossiers were reviewed by him during this period. It is important to mention that for at least half of these cases, the work up and conclusions regarding the described condition were perfectly clear and problem free. The other approximately half of this cohort had, however, not been given relevant or appropriate assessment, diagnosis or care – they demonstrated issues that were not described or dealt with relevantly at earlier stages of the disabling process. An example will elucidate the how and why of this problem.

## A CASE Story

A 35 year old male presents with severe lower back pains after a lifting trauma at his workplace some days earlier. The physician finds no dermatological issues but only muscle tenderness and orders some days’ rest and a standard NSAID medicine prescription. Some weeks later, the GP is approached by the community to deliver a physician’s note that the patient is not work ready. The GP calls in the patient, and he now has radial pains minding the GP of a slipped disc. The GP refers to the specialist route, and four months later there is an MR scan that shows clearly that there is no pathology in and/or surrounding the spinal column that can explain the patient’s symptoms. During the ensuing months, the social system fails to catch the MUS in this case, and first when the primary author is presented with the case after this period is the suspicion aroused that there is something here that does not add up. Through

interviewing and document mining, it turns out that the patient is dyslectic, passed his grade school with no referral to this phenomenon, could not do his basic arithmetic nor read as evidenced by the tests set in motion by the primary author. Refusing to take these issues into account and deal with them, the community awarded the patient a permanent disability pension based on his inability to work and the conclusion by all of the specialists (save the primary author) that the man was untreatable. The man is intelligent enough to realize where his shortcomings are, and this awareness has led to one experienced failure after the other until he no longer was able to handle the constant reminding of all which he could not do. This led to what can be likened to an early mid-life crisis which led to poor sleep habits and a generally tense muscle state that again led to chronic muscle tenderness which explains why the relatively light trauma in the story predicated the full blown pain syndrome that he ended up with.

Would this development have been avoidable? Obviously. The first step that falters is of course the parents and the school where the patient attended. They failed to address in time that the described individual was going to leave school without a reasonable modicum of what is needed to participate in a modern workforce. The next level of what goes wrong has to do the workplace per se, because the only work generally available to this type of young man is hard menial labor. The fact that hard menial labor tends to lead to early disability is extremely well documented (16,17). The negative effects of hard menial labor are often compounded by untoward conditions at workplaces of this nature, including insufficient machines and tools for lifting, poor ventilation and monotonous, routine work. Is this man treatable? Definitely. See more below.

## **Best Opinion**

The assessment that serious issues in the case described and the many thousands like it have not been uncovered during the disease generating process is based on the simple fact that these patients were in a more debilitated state than the description of their case could explain (n = approx. 5,000). This is not based on a concrete assessment using validated tools,

but rather the “best man’s best opinion”. We maintain that nothing better is available, and that this evaluation is good enough, given the enormous lack of relevant treatment modalities for the individuals in question. Given an average proportion of the population on sick leave at 7% in Denmark, this equivalates to roughly 3.5% of the population with some or other degree of MUS. Officially, there were in May 2005 157,000 persons in Denmark, or roughly 3% of the population, in social grouping levels 4 and 5, which in Denmark means that the person in question has work disability beyond what can be dealt with through standard work force related activities (18). The official and our observed percentages given here correlate well, but as described above, there is no hard data to corroborate this. This is not so important, however. Any epidemiological assessment has its uncertainties, and it makes little difference if the real figure is 2%, 3,5% or 5%. The problems for the individual patient and the cost to society are still completely unacceptable.

Given one accepts the prevalence estimate as reasonable, and that the figure is more or less uniform in countries with similar socio-economic conditions, it is relatively simple to extrapolate the yearly cost of disability pay and other costs for these patients, not the least of which is irrelevant usage of primary, secondary, tertiary and alternative health care and other resources. The following figures may help the reader. The support level and a rough estimate of health care usage for a Danish MUS patient is the equivalent of EUR 2,500 per month. Assuming that this patient does not return to the workforce, that the age of MUS onset is 35 years, and that the old age pension begins at age 67, then the discounted outlay from society in 2007 EUR is 2,360,000 (standard forward value calculation utilizing a 5% interest rate). Depending on the national tax level, this figure is roughly from 30% to 50% too low, as it does not take lost tax revenue into account. The interesting facet of this exercise is twofold: it elucidates the economic impact of MUS, and it puts into perspective that the cost of treatment of such cases is less interesting than whether it works. If the average cost of treatment is EUR 35,000, and the success rate is 50%, then the return on investing in treatment is a staggering 3,300% over 31 years (still assuming age of MUS onset 35 years and an average time of treatment one

year). As anyone familiar with investment thinking will attest, not investing in effective treatment of MUS patients is tantamount to financial suicide. Multiplying these figures by the total number of MUS patients world wide gives figures that defy the imagination. As stated above, the real figures are unavailable, but they are also not so important. The logic presented here fails to impress most politicians, as they tend to see only the cost of treatment, and either fail or refuse to grasp the long term advantages. This is one of the obstacles mentioned in the beginning of this article.

As stated above, very few published works show success in the treatment of this group of patients, and none of these have demonstrated the level of success we present here. The literature is almost wholly limited to the description of the group. There are numerous weaknesses in this work, the most serious of which is the lack of specificity and sensitivity of the instruments used. We maintain that this is an inherent flaw in nearly all clinical evaluations which is sorely accentuated in the MUS population. In the cited literature, the undescribed characteristics of the individual patient are a serious source of confounding. In our experience, the typical (see above) MUS patient has strong personal and individually unique experiences and characteristics that make grouping and categorizing useless at best, and counterproductive or even dangerous for the patient at worst (19). Besides the drug issues cited, this observation comes from the experience of the primary author as medical consultant and as clinical chief of the treatment modality described here, with N = 134 to date (number of patients examined).

## Recruitment of Patients

Patient recruitment for the group described in this publication has not been via a defined study nor through a clear clinical channel, e.g. referral to a cardiologist for chest pains and an abnormal ECG. The patients that are described here are all fringe patients with serious pain and/or psychological problems that every other clinical entity that exists in Denmark has defined as beyond clinical reach, i.e. the clinic in question has no treatment to offer. As such, patient recruitment has followed a pattern of being the

treatment of last resort for patients that have no other modalities available. Patients found us through word of mouth or by being described as needing the treatment modality described by the primary author in his function as medical consultant. The small number of patients described here in general and the even smaller number of those that have completed treatment is a reflection of the severe difficulty in getting payers of health care to understand how and why so much more can be done for these patients if one is willing and able to go the distance in long term care delivered locally and the implementation of the interprofessionality necessary for positive movement in the patient condition. That we have any results to publish at all is due to the largesse of a few Danish communities and a short period (nine months) during which we had a financing agreement with the Danish central hospital authority. This agreement was undermined by several factors, the most important of which is the same system intransigence to change that is touched upon above, despite the logic presented here. Other issues weighed in, among these the fact that the clinicians set to evaluate our reports had not the clinical knowledge necessary to do so, but that is another issue sorely in need of development and a book or two on the subject. As of this writing, the clinic has ceased to function due to lack of a workable financial model.

## Methods

The following sections of this article describe in some detail the examination and treatment of the MUS patient. Further information is available through contact with the primary author.

### *Patient Examination*

The examination is crucial to uncovering at least the main facets of the syndrome presented. No single exam can uncover all aspects of the syndrome for the simple reason that time does not allow this. Furthermore, the psychological genesis of the syndrome very often has elements that only come out when the patient is ready to report it. An example will elucidate this. Patient NN presents with a pain

syndrome which starts with a modest trauma to the left knee during a roller skating incident when she was 12 years old. The patient developed an untoward movement pattern based on persistent pains in her left knee. Over the 20 years that pass until we meet her, she has developed chronic pains in her back, the left hip and thigh as well as stomach pains tied to defecation problems. From the start, the symptoms did not reflect a common causality, and with time, the patient confided in us that she had experienced what in positive terms could be called bestial sexual habits forced on her by a psychotic “lover”. The point is not only that this case begs for the kind of help we can offer, but that each patient has her personal experience that condition the syndrome that ensues, and that this individuality precludes a standardized treatment approach. It makes no sense to rubricize this patient as having been through deviant sexual abuse, because no two patients so rubricized will have experienced enough of the same to warrant a standardized approach to treatment. Further, individual resiliency is sufficiently variable that some women will sublimate such experiences and be OK notwithstanding, and others will have varying levels of debilitating to extremely debilitating reactions thereto. This variability conditions an individual approach to the patient which a standardized modality is unable to carry out.

This being said, it is clear that the approach to the patient needs to be interprofessional, since no one individual health professional can cover the breadth of needed therapies and examinations to help and/or cure the patient. The patient described and all of her co-patients have various degrees of combined psychological and somatic symptoms that are closely tied to each other yet very difficult to approach due to the general phenomenon among these patients that they have accustomed themselves to their condition. They have their syndrome as part of their daily life and therefore part of their identity. Further, they are used to and have accepted the conclusions given that there is no treatment available. This altered identity can not be challenged without a reaction from the patient which in many cases presents a serious challenge for the interprofessional team. We have experienced several patients that simply would not put up with this challenge. We were forced to concede failure from the start, as these patients appear to be

completely uninterested in improving (20). To our knowledge, no systematical knowledge regarding this phenomenon (i.e. not wanting to get better) exists, although the issue is tangent to the neuroses of psychiatry.

More specifically and generally, the exam follows a reasonably common template, where the work-up of the treatment modality has to date been carried out by the primary author and a psychologist trained in pain assessment and cognitive therapy.

- The work-up starts with introductions and presentation of credentials for staff and patient. The process establishes the necessary decor and professionalism of the event, avoiding the risk of undue familiarity as well as ensuring reasonable cooperation (“we are here to help you, and we are qualified to do so”).
- Then we conduct a semi-structured interview. The interview varies much partly due to previous knowledge of the patient (other work-ups prior to our examination which we of course study prior to the exam when such is available) and the course of events in the individual patient history. Areas always covered include the full spectrum of patient life and health experience as much as patient memory allows. We cover birth and childhood, schooling, early adulthood and adulthood to date with full disclosure of relationships to spouse, parents, siblings, schoolmates and other relevant persons/institutions.
- Patient income, social relations and work history are covered. Special emphasis is placed on psychological health spanning life to date, and how this is correlated to employment or lack thereof.

This process takes up an hour to 1½ hours of interview time during which we in all but a few cases to date reach a level of empathy and trust with the patient that motivates her to reveal things that are deep secrets that few if any have ever heard before. This is partly due to our interview technique, which is highly culturally sensitive and patient centered (this also works through an interpreter), and partly due to

the highly unusual situation the patient finds him or herself in, spending around two hours with what for most of them is the first physician to take their complaints seriously.

After the semi-structured interview a structured interview regarding health issues is conducted, covering the usual sum of medically relevant issues: disposition, allergies, organ symptoms (including sexual health), medications, substance abuse, tobacco and alcohol use. The work-up then moves on to a full physical examination utilizing a mobile gurney that is carried along to every exam as well as the normal array of medical tools including stethoscope, ophthalmo/otoscope, blood pressure device, light source, tongue depressor, cotton swabs and reflex hammer.

During the work-up the physician and the psychologist supplement each other, take over the interview, tease a comment apart, fill in blanks, explain the odd misunderstanding and reassure the patient when one or the other oversteps a psychological threshold. In most cases, this leads to several outbursts of joviality, which increases patient empathy. The work-up gives the patient reassurance that the team is up to what it offers. All through the work-up, both the physician and the psychologist observe the patient – his/her movements, length of composure in one or more positions, facial expressions, emotional response range, normal, quasi-normal or abnormal behavior and responses and of course reactions to given instructions during the physical exam.

At the conclusion of the work-up, we explain our findings and the treatment strategy we envisage. We have not to date met any patients that did not accept our offer with two exceptions. These patients were brought to us by social authorities more or less against their will. In both cases we quickly discerned that the patients were neither interested in treatment nor in confiding their case to us, as discussed above.

Once we have our work-up back from the secretary, it is proof read and then sent on to the referring physician (clinical chief of one of the public clinics treating MUS patients) who evaluates the work-up and either gives it a go ahead or the opposite. This is highly problematical in that the referring physicians are generally not attuned to the psychosocial aspects of the case and therefore tend to

view our work-ups as insufficiently medical to warrant the green light for treatment to begin. Thus, a little more than half of the patients we have evaluated have not been treated. Attempts to turn this behemoth around have fallen to the ground so far and for reasons unknown to us, both the medical press and the daily press have been unwilling to take this serious problem up. We can only speculate that the failure to integrate our procedures into mainstream medical practice and media is due to the fact that our approach challenges the current medical-professional paradigm – if not “evidence based”, it can not be good.

In those cases where treatment (financing) is approved, it is instigated. Initially, emphasis is on creating trust and getting a fuller picture of the background for MUS, which normally is described during the work-up but rarely fully enough to allow a full picture of the therapeutic effort.

## Treatment

The novelty of this treatment modality is fivefold:

1. triage of the patient adheres to the principles outlined above. We assume that the patient has issues that are not described and delve into these issues during the primary exam. This requires a physician highly attuned to MUS and able to tease typical somatic problems and psychosomatic problems apart. The psychologist supports this and together the triage leads to the relevant treatment plan,
2. treatment is delivered in the patient's home or very close to there. There are four very good reasons for this:
  - the patient avoids the transport to and from the centralized service. For most patients, this is not an insurmountable obstacle, but for the chronic pain patient, the time and untoward seating in transport take more away from the treatment than can be given at the centralized unit,
  - after the session, the patient can sit back and relax instead of having to enter the transport home. The value of this is great, as most of our sessions leave the patient

- with heavy thinking to do and/or a deep relaxation state that is ruined by the stress of travel,
- entering the home gives the experienced clinician/therapist much information regarding the patient and her relations to others and her material surroundings that can not be gathered in any other way, and
  - the information thus gathered is instrumental in devising the next therapeutic thrust for the patient, especially in terms of the cognitive training. As described in various ways above, our treatment is highly individualized, although at the headline level it is the same for all MUS patients, i.e. cognitive training, relaxation and other therapies and medical advice, usually pertaining to reducing the number and amounts of medication the patient is on. Obviously, none of these activities can be planned or delivered in a standardized way, as each patient has her unique background, experience and reactions to the causing factors in MUS and to each session in the treatment.
3. treatment is delivered by individuals uniquely qualified in their fields. The primary characteristic of the individual therapist is a can-do attitude toward the combination of psychological and somatic experiences the patient exhibits. All of our therapists have a great wealth of experience and breadth of knowledge. This is in contrast to the sub-specialty setting where a specific and highly focused knowledge is necessary. Although probably not the deciding factor of our success, the choice of personnel is an important factor. It is obvious to us that our qualifications are unique, but hardly unattainable. The who, what, when, where, how and why of this is another area in stark need of development,
  4. our treatment is individualized based on the primary exam and the development of the case - see example below for an illustration of this. Further, the flexibility of the treatment allows us to bring in relevant experts on an ad hoc basis generally with very short referral times, either because they are "in house" (have a service agreement with our clinic) or they are able to put our patients in between other demands on their time, and
  5. back to work is the output variable. All of our patients are victims of long term sick leave and all have seriously wounded work mentality. The largest part of the therapy leading back to work is building resiliency that allows the chronic pain patient to master her pain sufficiently to let it go. The second largest part is to repair the wounded work mentality, and the third is to repair the surroundings of the patient keeping her in her straits. This includes the immediate family, the extended family where relevant and the work place when that comes to the fore. Again here, there is a huge and unmet need for developing personnel capable in assessing and massaging the workplace to accommodate the less than 100% fit.
- Besides these five items we do one more thing for our patients when funding allows: we continue the therapeutic effort until success has been achieved (back to work), or until we are not able to move the patient forward. This is in contrast to most treatment modalities that are delivered based on specific criteria meting out measured therapeutic regimes (the more and more common DRG concept). We are of course limited by what the payer is willing to pay, yet we motivate continuation of treatment in cases where the average modality has given up. This is motivated by our experience that has shown that even in the most difficult cases, good results can be had when the long run is financed. This point is in our experience the most difficult for the uninitiated to fathom. No system any of us know (and they are many) offers the breadth and scope of what it takes to bring the MUS patient securely back to the work force. They all demonstrate various shortcomings that condition the chain breaking with undue consequences for the patient, that through these shortcomings experience yet another failure of the system to understand them and take them seriously. For every failure of the system to

understand the MUS patient, the harder it is to reach them the next time around, in that the distrust fueled by system failure re-enforces the patient's perception that nothing can help them. We have numerous examples that qualify this which the reader is welcome to request if so desired.

The patients unable to re-enter (or enter) the workforce are "weaned" from our services cautiously, unless funding is suddenly revoked, which we have experienced more often than not. It is extremely important for the continued improvement of this group to give them a clear and candid picture of why they can not come back and how they can lead productive lives notwithstanding. This will often entail a protected work setting with a very limited number of work hours – 1 to 3 per day.

Treatment consists of a combination of therapies, including cognitive training led by a qualified psychologist, normally one visit per week but often more than that. The periodicity of this therapy is predicated by the need for the patient and her family to assimilate what transpired during the cognitive session, which always takes at least an hour and often up to two. Over the weeks, the patient becomes better attuned to the coupling between their emotional and psychological being and the concomitant bodily sensations, mostly pain related, that are tied to these. Obviously, this cannot be described in detail except at the individual patient level, since what actually transpires between the patient, her surroundings and the psychologist is highly variable and depends on individual characteristics, experience, resiliency pattern and emotional spectrum. The general strategy is to help the patient develop a clear picture of her response pattern to emotions and challenges in order to devise mastery tools that the patient can use to change her response pattern to a positive instead of negative pattern. Relaxation therapy supports this with various techniques described below. The patient is brought to more or less deep relaxation through these techniques, and this is a new sensation for most of our patients. They are used to being high strung, with little time during waking hours for themselves and even less time to relax and enjoy. Also these sessions are delivered in the home or nearby for the same reasons as for the cognitive therapy. As needed, other therapies are added ad hoc, the most common of which is physiotherapy. Our relaxation therapists

supplant physiotherapists in many respects, but not in the general area of muscle strength training and movement evaluation and training. Other common additions to the therapeutic regime are mainly diagnostic and are usually referred in order to rule out serious disease when symptoms mimic those of such, e.g. serious chest and stomach pains or pains in joints or muscles that warrant further investigation. Such examinations are carried out in the public health care system, which in Denmark functions very well as long as the issue in question is clear and limited.

In our work, it is common that changes in the patient condition reveal other aspects of the case which further temper and guide the therapeutic process. Each case evolves individually, but one example will elucidate the value of this approach.

## A Case Story

The patient in question has a minority religious belief and has grown up in a very restrictive environment under conditions conducive to the development of a dependent, escapist and externalizing personality. The woman in question is in her mid 30s and has two sons, both of which are bed wetters at the ages of 9 and 12. The husband is the same age as the patient and works full time in a non-skilled position – he is of the same religious belief as the patient. The patient's presenting problem is a chronic fatigue syndrome with varying and severe pains. She has been described, as have nearly all of our patients, as having been through every imaginable specialist work-up, none of which have turned up anything clinically useful and/or of any help for the patient. Our first impression was of a patient with massive and mostly unconscious psychological mechanisms that are 1) closely related to her physical symptoms both temporally and in severity and 2) clearly predicating the physical symptoms the patient has. As professionals working in this field, it is clear that one cannot describe this diagnosis to the patient off hand – it would make it impossible to start therapy with most of the patients with these symptoms, as they would be angered and frustrated by being told that their symptoms are mostly if not wholly explainable by character traits and dysfunctional reaction patterns. In this specific case, the patient had

been through a psychological treatment regime earlier and had been very put off by it.

Meanwhile, during the first few sessions, the patient began to thaw and it was demonstrable to her that the stresses in her daily routine had clear relationships to her symptoms. Although this was clear enough from the preliminary work-up, it took numerous psychologist sessions and guidance from the primary author to get the therapy on the right track, which included psychological tool building (cognitive training) around the dysfunctional reactions to improve the pattern. As the therapy was carried out in the patient's home, the relationships with her children and husband were evident and identifiable as elements in the problem complex. This underlines the value of the long term treatment plan and the delivery mode in the patient's home.

We utilize relaxation therapists in our treatment. There is as yet no licensure scheme nor a clear professional identity of this group which is comprised of therapists of extremely variable quality. Therapists are evaluated by us based on previous experience and curriculum vitae. Only the best are accepted as members of our team.

This patient had, as most MUS patients have, a generally stressed muscle mass with special tenderness and tenseness of the back and neck muscles, giving rise to a nearly ubiquitous headache tendency, which among MUS patients is often misdiagnosed as migraine or Horton's headache (cluster headache). Relaxation therapy in our clinic is carried out by qualified therapists, who focus especially on the interface between psychological mechanisms and bodily function. Cranio-sacral therapy, somatic experiencing, acupuncture and music therapy are among the methods utilized. None of these are well documented in terms of specific therapeutic results, but all are continuously evaluated in house in terms of patient satisfaction, seminal improvement signs and interviews. The soft nature of this data is a necessary disadvantage when dealing with the MUS patient. No double blinded, controlled protocol would allow the therapeutic effort into the inner workings of the patient complex, and a sensitive and tolerant therapeutic effort is neither measurable nor standardizable.

As the therapy evolves, we evaluate from week to week if other therapies are indicated and instigate

such as needed. Typical examples are warm water bathing/therapy with and without physiotherapeutic guidance, physiotherapy per se, consultations with other specialists, picture and/or laboratory diagnostic procedures and consultations with social and/or other authorities.

In the latter area, we make every effort to establish and/or reestablish the patient's work force related skills. This is carried out by specialized occupational consultants with a high degree of sensitivity to the problems the MUS patient has when returning to the work force, however light and easy the job may be. We spend considerable effort negotiating with the social authorities, who have the administrative and financial responsibility for optimizing the individual's work ability, but who rarely display understanding of the plight of the MUS patient. They rather have a prejudice regarding the MUS patient as being lazy or unacceptably socially dysfunctional and have a highly disconcerting record of doing more damage than good for the MUS patient (the primary author's own observations through five years experience as a full time medical consultant with 17 different municipal social services organizations). These negotiations and continued therapy during the re-socialization process (back to work) are central elements in our success rate.

## **Results**

Based on 18 completed therapy regimens, 10 are back in the workforce or doing education with a clear work targeted output. Also here, no standardized approach is relevant – each patient and each case worker has to be individually treated. The important point here is to make the effort. It leads to results.

We have not yet been able to follow a sufficient number of patients to generalize concerning the applicability of the described treatment modality. However, the rationale and logic inherent in delivery of treatment in the patient's home, the interprofessional approach and the full spectrum of treatment delivery, from the intensive medical and psychotherapeutic intervention via less intensive therapy to therapeutically supported occupational training, are resoundingly clear.

### Cost of Treatment

The treatment is expensive and highly demanding in therapy hours, but clearly worthwhile when over half of the patients thus treated return to the work force with all of the ramifications this has for the individual, her family, her community and society at large. Not investing in this endeavor is tantamount to writing a blank check to each MUS patient for life long disability pay. A rough estimate for the individual is as stated above approximately EUR 2,4 million, and a rough estimate of an average cost per treatment (including examination and the full spectrum of treatment including transport of staff) is EUR 35,000. It is not hard to figure the cost of doing nothing for MUS patients, which comprise approximately 3 percent of western societies, and other treatment modalities with worse than 50% success rates for back to work are saving that much less.

### Conclusions

The described modality is dependent on qualified personnel. The field is in stark need of development, both of trained personnel as well as relevant financing models. There is a significant lack of understanding among medical personnel of the scope and breadth of the problem, and none less than awareness of what to do about it. Given that the described modality can be generalized and disseminated, there is no reason why at least half of the MUS disabled population can be brought back to the work force, resulting in enormous personal, professional and economic benefits.

It is clear that western societies have a serious and growing problem with that proportion of the population that does not fit the mold, is not able to function 100% under normal conditions. We are hurtling down the track with destination Evidenced Based DRG. Unless we develop flexible and tolerant financing for effective treatment for MUS patients, we can not expect the cost of supporting them to come down. We have shown a way that works.

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