Review

Fibromyalgia and the therapeutic domain.
A philosophical study on the origins of fibromyalgia in a specific social setting

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Objectives. Fibromyalgia has always attracted controversy. Wolfe states that fibromyalgia will always exist regardless of the name given to the syndrome. Hadler describes fibromyalgia as a form of illness behaviour escalated by labelling. However, we believe that fibromyalgia, as other functional somatic syndromes, is not waiting below the surface until it becomes manifest by labelling.

Methods. We developed our hypothesis on the relationship between a specific social setting (called the therapeutic domain) and fibromyalgia using empirical philosophical arguments based on Foucault and Hacking. A therapeutic domain is a real and heterogeneous medical domain in which people, their thoughts and practices, and medical technology in any form coexist and communicate. In this domain blood is aspirated, radiographs are taken and classification criteria are made and applied. It is a domain where patient and therapist have initiated a relationship, which is influenced by the media and political pressure. This results in a looping effect where classification criteria and images give structure to perceptions and form the description for human behaviour; the person thus diagnosed (!) constantly has to grow into the conformity of these classification criteria, which also have to be constantly revised. The fibromyalgia concept becomes manifest in an individual as non-specific aches and pains along with other features.

Results. In other times and settings this resulted in analogue syndromes like railway spine, telegraph wrists, neurocirculatory asthenia or perhaps repetitive strain injury. In the application of American College of Rheumatology fibromyalgia classification criteria, labels and medical technology it is possible that invisible experiences manifest themselves in a therapeutic domain. It is not only a phenotype induced by the physician, but in this domain a certain power creates reality making the ‘disease’ become manifest.

Conclusion. The only certainty in fibromyalgia is that it is still being diagnosed. For prevention and treatment of fibromyalgia, doctors as well as politicians and media have to start by fundamentally changing the therapeutic domain. In such a renewed setting, fibromyalgia cannot become manifest in an individual and thus fibromyalgia syndrome can no longer exist. A firm public message that symptoms can be psychological in origin to prevent their spread, as Wessely recently stated in the comparable case of mass psychogenic illness, is only a part of the answer.

KEY WORDS: Fibromyalgia, Functional somatic syndromes, Therapeutic domain, Doctor–patient relationship, Medical technology, Representation of diseases, Philosophy of fibromyalgia.
Introduction

Physicians are unable to demonstrate fibromyalgia as a visible disease. It ‘occurs in the context of unrevealing physical examination and laboratory and radiological examination’ [1]. Fibromyalgia is ‘not an entity that can be described and explained; it is rather a subjective experience comprising pain and fatigue’ [2]: ‘a puzzling syndrome’ [3, 4]. But at the same time these invisible personal experiences have a visible (form of) appearance: the fibromyalgia syndrome [5]. From a positivistic point of view, fibromyalgia cannot even exist because we cannot demonstrate it objectively [6, 7].

Hadler states that fibromyalgia is a form of illness behaviour escalated in vulnerable patients by labels [8, 9]. However, we hypothesize that fibromyalgia behaviour is facilitated by medical and therapeutic practice, called an ever-changing ‘therapeutic domain’. Behaviour is defined as: the form of nervous, muscular and emotional response of an individual to internal or external stimuli [10]; in our opinion like all instincts or actions of the central nervous system including the autonomic part.

The therapeutic domain

The therapeutic domain is a social setting, called ‘a matrix’ by the Canadian philosopher Ian Hacking, within which an idea, a concept or kind is formed [11]. It also is a domain within which a sufferer asking for help may or may not become a patient, a reason why we speak about a therapeutic domain instead of matrix. This domain is always within the sphere of influence of a physician or another health professional, be it the waiting room of the rheumatologist, radiology department or a medical ward in a hospital. A therapeutic domain is a real and heterogeneous medical domain in which people, their thoughts and practices, and medical technology in any form coexist and communicate. In this domain blood is aspirated, radiographs are taken and classification criteria are made and applied. It is a domain where patient and therapist have initiated a relationship, which is influenced by the media and political pressure. This results in a looping effect where classification criteria and images give structure to perceptions and are ratified. Likewise, the patient has expectations of the success of any therapeutic intervention and yet pain is stalking the domain like a phantom, raising questions concerning reality, truth and severity of pain and suffering. Similarly, there are questions, covered by taboo, about contributory factors which may be psychological in nature or which may involve previous sexual or physical abuse.

This domain constitutes what Hadler calls ‘the settings where the hunt for a diagnosis can be harmful to health’, or ‘the vulnerable and disputative state’ [8, 12] and therefore it is important to clarify that domain. It is part of what the French philosopher Michel Foucault called the tertiary, societal or—in some cases—medical domain or configuration [13]. The therapeutic domain is more than a treatment act. It is the social setting within which a particular treatment act plays out, a setting which, in our opinion, has received much too little attention where fibromyalgia and other syndromes are concerned. This setting has the capacity to generate within its confines a new representation, and thus a new syndrome. It is the domain where people can label their internal sensations as illness or disease [14].

 Syndromes like fibromyalgia are thus not waiting below the surface until they are discovered by a researcher or brought to light by the medical gaze. Fibromyalgia cannot be regarded as ‘an age-old malady begging for respect’ [15]. On the contrary, one could say that in a therapeutic domain a certain power creates reality and hence a form of visible presentation. The appearance of this presentation will change in the course of time, hand in hand with changing diagnostic techniques and technology and with classifications becoming ever more subtle [16–18]. Most patients labelled as having fibromyalgia have a past medical history that is remarkable for somatization whether or not they have sought labelling or treatment acts.

It is important to mention that a specific therapeutic domain is necessary, but not sufficient, for the manifestation of certain complaints we now call the fibromyalgia syndrome. We want to emphasize that neither a therapeutic domain nor doctors can be held responsible for either causing or perpetuating this disorder in people. We have to make a difference between the concept fibromyalgia and the individual patient. We will make some remarks on this important difference in the discussion and conclusion.

Fibromyalgia

The typical sufferer is a middle-aged person, most often a woman, who seeks help from his or her family doctor because of complaints which he or she has experienced over a period of several months. The pain is vague and affects the whole body, and is associated with listlessness, disrupted unrefreshing sleep and it is usually accompanied by constipation or abdominal pains. There are no clinical findings suggestive of chronic disease. Then the family doctor decides to perform further blood investigations, but each is normal, as are the radiographs. Analgesics have little or no effect. The rheumatologist to whom the patient is referred counts the tender point score and repeats many of the investigations; although the doctor realizes that the tender joint score is not necessary for making the diagnosis, as these are not specific [19–21] and tender points may ‘only be accessible to the finger of faith’ [22]. The information that the patient obtains from glossy magazines, the Internet [23] and friends and relatives confirms his or her belief that he or she has fibromyalgia. The rheumatologist, seated in front of popular (female!) anatomical illustrations of tender points on the wall, explains the syndrome with an illustrated patient information leaflet and a glance at the American College of Rheumatology (ACR) 1990
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classification criteria [24]. By this time he or she has become a member of the fibromyalgia patient self-help group. Within this therapeutic domain this person has been able to give embodiment to her symptoms as a fibromyalgia patient. Simultaneously, an organizing, reality-forming power of that domain has structured the observation of family doctors and rheumatologists. A so-called looping effect [11] has taken place: the individual patient and the concept have influenced each other.

In a different therapeutic domain this person could be diagnosed and classified from a different perspective using other criteria. Fibromyalgia is called one of the functional somatic syndromes known by different names by many medical specialists [25, 26]; these syndromes are also called central sensitivity syndromes [27]. After referral to a psychiatrist, the fact that he or she had been abused as a child might now be interpreted as a cause for the condition, although this relationship is inconsistent and hard to validate [28]. Satisfying DSM-IV criteria, he or she could have been classified as having a chronic pain disorder associated with psychological factors or with both psychological factors and a general medical condition [18]. Had he or she been referred to the gastroenterologist this person would perhaps have been diagnosed as having irritable bowel syndrome [8, 29] and in the case of referral to the neurologist or internist as having chronic fatigue syndrome [29].

Discussion

Although ‘it is increasingly accepted that this fibromyalgia syndrome is a definable clinical entity’ [5] using the classification criteria [24], the syndrome is still disputed, and in a sense by and large invisible. And paradoxically, according to the same criteria, it is at the same time visible in another sense: a ‘recognizable syndrome’ [30], a ‘readily recognizable clinical entity’ [31], ‘can be identified’ [32], ‘real, not fabricated or imagined’ [33], and ‘common’ [34] or even ‘near epidemic’ [35]. Like mass psychogenic illness [36, 37] fibromyalgia seems to spread through social networks.

Fibromyalgia can be diagnosed without excluding visible, somatic and incurable diseases [24]. Still, the doctor is morally burdened to exclude such diseases, for fibromyalgia occurs in the context of normal examination findings and negative investigation results [1, 38] resulting in a cascade of diagnostic technology being let loose on the patient. When the diagnosis is made, the patient may respond with hostility to any suggestion that psychological factors may be contributing. These factors have become a taboo for both patient and doctor [8, 9, 32, 39]. The same can be said about not coming to terms with a traumatic event, for example incest [40-43]. The sufferer is obsessed with the alarming thought that more movement will lead to more pain as well as more tissue damage [44]. He or she knows that patients with established disease have uniformly poor outcome [45, 46] and that the disease is expensive [47] and treatment of limited effectiveness [48]. The patient’s illness behaviour now becomes automatic and perhaps he or she will gloomily enjoy the secondary illness gain [49].

‘To be well, to feel invincible, is to have the personal wherewithal to cope with both the physical and the psychosocial challenges. If our homeostasis is overwhelmed, we transform our distress into a narrative that is culturally defined and constrained’ [50]. This coping difficulty is sometimes seen as the main cause of fibromyalgia. Lorentzen [51] states that fibromyalgia is not a disease entity, but the symptoms often reported supposedly reflect difficulties in coping with various types of environmental stress. He sees this as the key in the process and therefore that identification of these environmental factors and subsequently early intervention should have high priority. The experienced stress may lead to sleep disturbances, fatigue and a low level of physical activity and fitness, leading to muscle pain and tenderness, becoming a vicious circle.

People seek medical care and enter the health care system generally due to the experience of physical symptoms, especially when they are persistent. For example, eight common physical complaints (fatigue, backache, headache, dizziness, chest pain, dyspnoea, abdominal pain, anxiety) account for more than 80 million visits annually in the USA [52]. However, demonstrable organic cause can be identified for less than 24% of these symptoms [53]. Health care costs of these patients are 10 times higher than the average patient [52]. Katon et al. [54] found that 10% of primary care patients account for almost one-third of out-patient primary care visits, one-half of hospital days, one-half of specialty visits and one-quarter of prescriptions. These high utilizers had a mean of eight to nine medically unexplained symptoms over the course of their lives.

People with ‘established fibromyalgia’ have reduced quality of life with abnormal scores for pain, disability, psychological status etc. [45]. The quality of life is even worse than that of people with rheumatoid arthritis or osteoarthritis, and comparable with severe pulmonary disorders and insulin-dependent diabetes mellitus [55]. Fibromyalgia often coexists with other common, ill-defined syndromes such as chronic fatigue syndrome, headache syndromes, irritable bowel syndrome, restless legs syndrome and depression [27, 56].

When do symptoms become a disease?

‘Although biological and clinical factors have set boundaries for which symptoms might plausibly be linked in a disease concept, social influences have largely determined which symptom clusters have become diseases’ [57]. The last strategy commonly used to legitimize symptom clusters as diseases is probably the most prevalent today: the use of consensus panels, such as those that have produced the diagnostic and statistical manuals for psychiatric diagnoses’ [57]. Classifications of diseases are easily used then as diagnoses.

Do we (physicians, sufferers, health professionals, employers, politicians and others) need a concept of disease? We agree with Hesslow stating: ‘The concepts
“disease”, “health”, and “illness” do not play any significant role in medical science [...] the concept of disease is superfluous. It may be useful in everyday affairs, where sophistication would be out of place, but in more serious contexts it is misleading and an obstacle more than a help to clear thinking. A strong emphasis on the distinction between health and disease in medical philosophy is thus misguided’ [58].

‘Disease is generally considered to be an attribute of a patient, whereas diagnosis is the belief that the patient has a disease, a belief that may or may not be true. In using a single phrase to describe a set of clinical findings, important information can be effectively communicated to other clinicians and care providers. [Classifications used as] diagnoses are intended to inform patients and to tell clinicians who and how to treat. Labelling someone as “diseased”, however, has enormous individual, social, financial and physical implications. Irrespective of disease symptoms, the label itself may lead to significant distress’ [59]. ‘Two schools—nominalist and essentialist (reductionist)—have debated the clinical criteria used to label a patient as diseased. Nominalists label symptoms with a disease name, such as schizophrenia, and do not offer an explanation of the underlying etiology. Essentialists argue that for every disease there is an underlying pathological etiology and that the disease state should be defined by the essential lesion’ [60]. It is clear, diagnoses are not diseases [61].

But even non-diseases play a role in the daily practice of every doctor. In his brilliant and hilarious article Meador describes: ‘Latent nondisease lurks in every patient. It becomes overt as a specific entity usually in the hands of a physician, nurse or technician, but occasionally through the lay press or “friends” of the patients. Latent nondisease is always desirable’ [62].

In a special issue of the British Medical Journal, Smith reminds that: ‘The concept of what is and what is not a disease is extremely slippery. It is easy to create new diseases and new treatments, as many of life’s normal processes—birth, ageing, sexuality, unhappiness and death—can be medicalised’ [59, 63].

The perspective of sociology of knowledge
From the perspective of sociology of knowledge there is a difference between our point of view and the biopsychosocial model. Wolfe et al. [31] state that the ‘bio-psycho-social-model may well be the appropriate descriptor for the syndrome’. They presuppose that fibromyalgia exists and that it is caused by multi-dimensional factors that can be described and explained. In philosophical terms they have a positivistic point of view. It is what is described as a ‘whig-history’, i.e. a circular argument beginning with what is evident in the present and explaining it from past events [64].

Our philosophical, dynamic, realistic point of view is that it is not appropriate to think only in terms of causality of the central neuron and peripheral level in the body of people diagnosed as having fibromyalgia. In our opinion it is more appropriate to consider the therapeutic domain creating a concept of a disorder in the way it is now recognized in and by the individual patient.

We agree with Hadler when he quotes Meador [62] by saying that ‘labeling of a nondisease can cause patients to perceive themselves as ill’ [9], but we disagree when Hadler states [8, 65] that fibromyalgia is only the result of ‘iatrogenic diagnostic algorithms’. Labelling by doctors. Our hypothesis is that patients shopping around for a diagnostic label that fits them and does not stigmatize them as not being ill is just an aspect of ‘the construct fibromyalgia’ [66]. We state that only labelling within a certain therapeutic domain will provide them with a socially accepted legitimacy. If a description doesn’t exist, then the sufferer cannot intentionally adhere to the described disorder. Like any form of intentional human behaviour a label only represents behaviour ‘under a description’ [67]. Concepts or classifications of diseases interact with the human beings who are classified according to Hacking’s looping effect [11]. Hadler suggests that it is the doctor who gives direction to the patient’s symptoms, given there is something physical, perceived by the sufferer [8, 11, 65]. We believe that ‘we must speak of that initial dispute without assuming a victory’ [68] and that a therapeutic domain creates their symptoms, not necessarily those produced by the doctor’s questioning.

It is not only the classification criteria in rheumatology, changing in time [24, 38, 70], that define the disorder, because at the same time these criteria and the image formed of the disorder also have organizing and reality-forming power: the perception of the medical profession is structured and structuring and the classifications and the people who are classified interact. That is the looping effect. There is also the imagination of the individual doctor, ‘stories’ and multimedia images of (female) bodies on which the 18 ‘specific’ tender points are indicated. There are also many hypotheses about the (supposed) cause(s) or inducers of the syndrome, for example: sleep disturbance, daily hassles, neuroendocrine disturbances [27, 28, 46, 71, 72], C6-7 syndrome [73], microtraumas in muscles, cervical spine injury, any physical trauma, infections like Lyme disease and low back pain may induce fibromyalgia as well as social and cultural factors, psychic and psychiatric disturbances, incest and child sexual abuse [1, 28, 40–42, 56, 74–79].

Even though these associations are likely to be spurious, the therapeutic domain is liable to render them part of the narrative of illness of ‘fibromyalgia’, if not idioms of distress similar to ‘tender points’ [3, 19, 80–83].

In the development of fibromyalgia, one is giving credence to making visible something that is not universally present and accepted. A process in which, together with this making visible, meanings arise and change, and doctors and patients repetitively assign complaints and symptoms to other events. This process is called aesthetic representation [84, 85]. So, by representation we do not mean so-called mimetic representation according to which one point is being imagined from another, like in a mirror, but representation as substitution. According to this concept of representation,
a discrepancy exists between what is represented and what represents ‘as real as the real difference between a painted portrait and the portrayed’ [86].

In the case of multiple personality disorder, sleep disorder has been ascribed to previous sexual abuse leading to sleep disturbance. In fibromyalgia, sleep disturbances are thought to be central as well [23, 87, 88]. According to an aesthetic representation process, it was to be expected that articles have been published ascribing fibromyalgia to sexual and/or physical abuse [40–43, 89]. Thus representations are formed, and ultimately a representation of fibromyalgia.

Fibromyalgia is described as an ‘affective spectrum disorder’ [90] or as a component of the ‘dysfunctional spectrum syndrome’ [91], in any case chronic widespread pain may be a feature of somatization at the turn of the twenty-first century [92–95]. This somatization, a social accommodation that allows people to express distress passively through physical symptoms when direct expression would be too threatening [96], is a universal human propensity, with distinct regional dialects [97], resulting in ‘fashionable diagnoses’ [92]. In Singapore factories, for instance, mass psychogenic illnesses have involved convulsions and combative behaviour [98], while in Western workplaces dizziness, fainting, headache and nausea predominate [99]. Hunt et al. [100] found an association with two specific illness attitudes associated with chronic widespread pain (hypochondriac beliefs and bodily preoccupation), both of which have been suggested as important features in the subjective reporting and amplification of pain syndromes [101]. A physical complaint is the result of the physical situation and the psychological observation, perception, interpretation and reporting strategies [14, 102]. The over-reporting of complaints by women may be explained by gender differences in the way women perceive physical symptoms [103].

Women incline more to somatization, negative affect and pay more attention to physical sensations than men [104]. The term somatization gives reason for dispute. We agree with Hadler stating: ‘The very term, somatization, harkens back to the heyday of psychosomatics, earlier in this century, when psychic conflict was thought to be convertible into physical symptoms. Somatization is a stigmatizing label; it belittles the symptoms as if they are not real, somehow feigned, perhaps serving some subliminal secondary gain. I would argue for abandoning both the terminology and the line of reasoning’ [105].

The American Psychiatric Association categorized fibromyalgia as a ‘somatoform’ disorder. A separate category was devised for this spectrum of illness, ‘somatoform disorder not otherwise specified’, defined as: ‘medically unexplained symptoms and worry about physical illness may constitute culturally shaped “idioms of distress” that are employed to express concerns about a broad range of personal and social problems without necessarily indicating psychopathology’ [105].

In a recent editorial, Ross [96] describes ‘memes’ as ideas that induce psychosomatic illness. These psychosomatic memes induce biological, psychological and social changes in their hosts and can be transmitted to others. He uses the meme construct in an allegorical sense and we have some difficulty with the meme construct as an infectious particle of thought [106]. In our opinion this fascinating concept can only evolve, spread and endure within a therapeutic domain. We would say that memes and the therapeutic domain ‘emerge hand in hand’. This view parallels the ideas of Foucault and Hacking about the category and the patient [13, 107].

Foucault’s [108] ideas regarding ‘the constitution of the subject’ is called ‘dynamic nominalism’ by Hacking [11]. The latter calls his own less constructivistic ideas ‘making up people’ [11, 107]. Foucault did not develop the idea of therapeutic domain, but described forms of behaviour which develop from the invisible to the visible within what Hacking would call a matrix many years later and we call a therapeutic domain [109]. Historical examples have shown us more syndromes with typical behaviour, such as the railway spine [110, 111], writers’ cramp and telegraph wrist [112], hysteria including the ‘arc de cercle’ [113, 114] and epidemic neuromyasthenia [115]. Royal Free epidemic [116] and more recent ‘epidemics’ [117, 118] like the rise and fall of the repetitive strain injury (RSI) epidemic in Australia [119–121], multiple chemical sensitivities [92, 122], pseudohypoglycaemia [123], whiplash epidemic [124], neurasthenia [113], chronic fatigue syndrome or epidemic encephalomyelitis [117, 118, 125] and perhaps the Gulf War syndrome [126–128], the multiple personality syndrome [109, 129] and homosexuality, which the Board of Trustees of the American Psychiatrist Association in the beginning of 1974 decided to include no longer as a psychiatric disorder coded in their third manual [16, 17, 130]. They illustrate that such syndromes are not just the products of labelling, categorizing or memes. In that sense our view differs from other multidimensional or biopsychosocial models of disease [30, 131, 132].

**Conclusion**

Our hypothesis is based on a multidimensional view of fibromyalgia and presupposes that physical as well as cognitive, emotional, behavioural and social factors participate in this syndrome. The form of representation to which these factors will lead to is dependent on the therapeutic domain and not only on labelling or ever more subtle forms of classification. We must conclude that, given these factors, a certain therapeutic domain creates a syndrome in a person with non-specific aches and pains with a tendency to somatize, and with insufficient coping behaviour. In that case we may describe it as the phenotypic iatrogenesis of fibromyalgia. So it is not a disease but also not a constructed syndrome.

There is a reciprocal, dynamic relationship between doctor and patient, between classification criteria and behaviour, laboratory results and symptoms as well as expectations created by the media and what we actually achieve in our lives within a therapeutic domain. A result of this looping effect is that when (other) classification
criteria and images give structure to perceptions and are ratified, the structure of the therapeutic domain changes. The person thus diagnosed (!) will have become a different person, and grows into the conformity of the classification criteria, which have to be constantly revised [129]. These alterations in an ever-changing therapeutic domain make the new facets of the disorder possible and manifest. There is something like fibromyalgia, but her manifestation or phenotype, is developing. Let it be clear, we do not state that a specific social setting or just a doctor causes symptoms, disorders or an individual patient who would otherwise have been absolutely healthy. No, in a therapeutic domain a concept is constructed, technology developed, classifications made and they interact with the people who are diagnosed and classified. Believers in fibromyalgia as well as the sceptics and agnostics will see the same people, but the latter do not allow the sufferer to behave in a fibromyalgia-phenotypic way within their therapeutic domain.

As Reilly puts it: ‘That the diagnosis (fibromyalgia) has gained credibility cannot be doubted. ... In fibromyalgia, we may have created a monster. Is it now clinically, socially and financially appropriate to slay that monster?’ [133].

In contrast to Goldenberg [1], we suppose that patients diagnosed with fibromyalgia syndrome do not represent ‘a uniform set of symptoms and signs’. The rise and fall of the railroad spine, the telegraph wrist, hysteria including the ‘arc de cercle’, the RSI epidemic in Australia, multiple chemical sensitivities [92], pseudohypoglycaemia [123], whiplash epidemic [124], neurasthenia [113], the multiple personality syndrome [109, 129] and homosexuality have taught us that Wolfe’s [35] assertion that ‘fibromyalgia will always be with us ... regardless of what name the syndrome’ has, is unlikely to be true. The concept of the syndrome has been changed by what we call it and because of the looping effect the individual patient has been changed also. Using the ideas of Hacking [107] we could state that there are two powers. One is a power ‘from above, from a community of experts who create a “reality” that some people make their own’. The other one is a power of the autonomous behaviour of the person so labeled, which presses from below, creating a reality every expert must face’ [107]. Psychiatrists and psychotherapists are no longer needed to label somebody as a homosexual or as having a multiple personality. Their role has been taken over by the gay community and the multiple world [109]. In the same way, rheumatologists are no longer needed to label someone as a fibromyalgia patient. Their role has been taken over by the fibromyalgia patient organizations. The only certainty in fibromyalgia is that it is still being diagnosed.

Science has had and will have much to offer for the diagnosis and treatment of diseases. But society and medicine have to turn to philosophy rather than to science for the solution of treating and preventing ‘syndromes’ like fibromyalgia. A firm public message that symptoms can be psychological in origin to prevent their spread, as Wessely [134] recently stated in the comparable case of mass psychogenic illness, is only a part of our answer.

For prevention and treatment of fibromyalgia we have to start by fundamentally changing the therapeutic domain. In such a renewed setting fibromyalgia cannot become manifest in an individual and thus fibromyalgia syndrome can no longer exist.

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