

Shared Spaces for Reflection: Approaching Medically Unexplained Disorders

When doctor and patient meet, the doctor is expected to find out what causes the patient's problems, and what can be done about them.¹ In the diagnostic process, the patient's presentation of symptoms is perceived, interpreted, and judged by the doctor. The patient's story is supplemented by other sources of clinical knowledge, such as tests and clinical examinations, medical science, and the preconceptions and experience of the doctor. The doctor's interpretation is fed both from the medical and cultural spheres.² In the majority of consultations, the patient's story provides stronger clues for diagnosis than the clinical and laboratory-based examinations.³ Yet, the patient's voice does not always count.

DECODING THE PATIENT'S SYMPTOMS

Medically unexplained disorders (MUD) – conditions with subjective symptoms, where objective findings or explanations are missing – is a cluster concept for chronic disorders which do not fit traditional biomedical categories.⁴ These conditions challenge the biomedical foundation of clinical diagnosis and interaction.⁵ The majority of patients are women.⁶

Patients suffering from an illness which does not leave footprints observable by the medical gaze are often met with lack of understanding by the doctor. Among patients with chronic pain or fatigue, a recurrent complaint is their feeling of not being taken seriously by the doctor.⁷ When doctor and patient do not share explanatory models, their interaction is hampered by tensions which can obstruct the decoding of symptoms and the subsequent process of understanding and management.

In the research network known as "Symptoms as a Source of Knowledge" (Bergen/Norway 1993-2001), we set out to explore possibilities for transcending such tensions by creating common ground between doctors and patients suffering from medically unexplained disorders. Our focus concentrated on female patients, exploring particularly the impact of gender. In this article, however, we take a broader perspective, synthesising the findings of many

empirical studies from the network which are applicable to women as well as men. The aim of this approach is to develop concepts and hypotheses that would help clarify the conditions necessary for acknowledging patients' voices and symptom descriptions as legitimate sources of medical knowledge.

METHOD AND MATERIAL

"Symptoms as a Source of Knowledge" was a research network consisting of 23 researchers from six different disciplines in five countries. Studying MUD in women, we shared the assumption that the patient could provide important contributions to new understandings of these conditions. During the decade 1993-2002 we conducted 17 separate studies exploring experiences with symptoms, causal explanations, and health care experiences in women with chronic pain, chronic fatigue syndrome, tension headache, genitourinary problems and pelvic problems in pregnancy. For comparative purposes, a study of women with Sjogren's Syndrome was added. Sjogren's Syndrome is a rheumatic disease which initially presents without a medical explanation, with the biomedical markers appearing 7-11 years later. The analysis presented below is drawn from empirical findings in publications by the research network (29 articles in review-based journals, 12 reports, and 15 articles or book chapters addressing a public audience – of these, 12 were presented in an anthology published in 2001). Since several of these publications were written in Norwegian, we have supplemented the material for this presentation with related articles in English, although they were published later.

ANALYSIS

The analysis was conducted through collaboration between the two authors, Kirsti Malterud, a general practitioner with clinical and research experience of MUD, and Arnhild Taksdal, a social scientist with experience of analysis of texts representing various marginalised subject-areas. Both authors shared a feminist frame of reference, implying an explicit awareness of the relations between gender, power, and culture. We chose a pragmatic approach related to meta-ethnography,⁸ based on systematic review and reflection on material drawn from the separate studies from the network, relating their individual content to the theoretical framework which we present below.

In the first stage of our analysis, we read through all the material to identify recurring issues. These issues were applied to the theoretical framework (presented below), in order to develop analytic questions for the second stage of the analysis, where we reviewed all the material to develop hypotheses about various obstacles to and methods of transforming patients' symptom descriptions into sources of medical knowledge. These hypotheses were further used to discuss conditions which might shape and influence clinical diagnosis, especially for women suffering from MUD. The theory, method, empirical data, and findings of the synthesis have previously been presented in Norwegian in preliminary form.⁹

RHETORICAL SPACES – THEORETICAL FRAMEWORK

Our point of departure is the theory of social constructivism, regarding knowledge as the outcome of interaction and interpretation within a wider social and cultural context. Hence, the implicit and explicit rules of the clinical encounter shape the understanding of the causes of the patient's problems, of the underlying origins of disease, and what can be done to treat, alleviate, or cope with the problems.

Doctor and patient both carry a broad range of knowledge and preconceptions, including unconscious, tacit knowing, cultural experiences and stereotypes, which shape their explanatory models and understanding of illness.¹⁰ Code has presented the concept of *rhetorical spaces*: social locations whose tacit rules structure the messages that can be voiced with a reasonable expectation of being heard, understood, and taken seriously.¹¹ Framed by the rules relating to these rhetorical spaces, certain expressions will be acknowledged, while others will not. This is not because they are false, but because they are the outcome of power-induced practices that disqualify certain expressions of voice. Within the rhetorical spaces ruled by biomedicine, the doctor's observations have a stronger currency than the patient's experiences. These discourse practices are also gendered.

We reviewed the empirical findings from the research network, seeking possibilities for transforming the rhetorical spaces of the medical encounter into discourses where the patient's perspectives would be included as valid sources of clinical knowledge.

RESULTS

In the first stage of the analysis, we identified four recurring themes in the material:

- Both doctor and patient seek *biomedical references* to the patient's complaints, associating such findings with the *credibility of the patient*.¹²
- The *distinction between trivial ailments of everyday life* and some of the symptoms associated with medically unexplained disorders can appear blurred. Furthermore, the symptoms often overlap, vary, and change over time.¹³
- The doctor *neither perceives nor acknowledges the patient's symptom story*. Even the patient can have problems recognising his or her symptom experience as valid knowledge, which in turn may impair his or her bodily awareness.¹⁴
- Strategies for management which explicitly *acknowledge* the patient's voice and symptoms can create possibilities for dialogue, relationship and self-reflection, leading to a mutual increase in competence between patient and doctor.¹⁵

These observations have made us reconsider some basic elements of the process of knowing and clinical interaction. Any process of knowing requires that we transform what we seek knowledge about into an object of investigation – actively, by *objectifying* it. A certain distance will always be needed for this purpose. Any reference to something other than the concrete part of reality we strive to understand will establish such a distance – a *space for reflection*. Elaborating this concept further, we propose that it is possible to create several different spaces for reflection in order to achieve our aim – for instance, by comparing the actual case with

another one, or exposing it to theoretical perspectives, analytic concepts, or preconceived or stereotypical schemata for interpretation. Objectification – creating an interpretive distance in order to make the patient’s complaint an object of study – is a legitimate and necessary strategy for the development of knowledge, and can be used by the doctor to understand what is wrong with the patient.¹⁶ Yet, different kinds of spaces for reflection will lead to different processes and outcomes, depending on who is participating and the implicit rules which regulate their interaction.

In the second stage of analysis, we reviewed the empirical material again, this time looking specifically at the impact of different spaces for reflection where objectification would take place. We explored various contextual and discursive possibilities for more-or-less successful decoding of apparently unexplained disorders, with a special eye on the relationship between interpretive interaction and a variety of different outcomes. Our search was guided by these questions:

- How does the doctor “navigate” in order to objectify and achieve distance?
- How is the object of such objectification determined?
- Which biomedical, cultural and ideological assumptions have an impact on the rhetorical spaces where medically unexplained disorders are negotiated?

Below, we present a number of concepts and hypotheses drawn from this analysis.

INTERPRETING SYMPTOMS – NAVIGATING BETWEEN REFERENCES OF VALIDITY

In the diagnostic process, the patient’s “signs” will only be included as valid for developing knowledge insofar as the doctor perceives, identifies, and recognises them as relevant. The ability to distinguish and identify clinical conditions is rooted in the doctor’s available repertoire of significant patterns of meaning. By recognising a certain pattern of meaning from symptom description and clinical examination, the doctor establishes a reference to the underlying meaning and impact of what is heard and seen. We found that patterns traditionally recognised as intelligible were easier to observe, and that deviations with clear-cut boundaries were more readily acknowledged than those without.

- Observing and identifying significant patterns

Many medical signs have immediate reference to intelligible patterns, representing a legitimate or obvious entity or criterion of disease. For example, an increased level of blood glucose indicates diabetes. However, the atypical symptom descriptions which do not appear in the textbooks are not as readily recognisable. The doctor who has learnt that cystitis is synonymous with dysuria would not necessarily recognise or see the relevance of this symptom description from a woman with lower urinary tract infection:

Sometimes, when I go to the toilet and pass urine, I feel a pain in my wrists.
(our translation)¹⁷

However, the wrist pain is not necessarily a meaningless or non-existent phenomenon just because it is atypical. In a group interview, women with Sjogren’s Syndrome gave several new symptom descriptions.¹⁸ These appeared immediately intelligible since they could be explained

by underlying immunological mechanisms. Specific descriptions of acute chest pain might, for instance, indicate hypotheses of pathogenetic mechanisms such as Raynaud's phenomenon in the oesophagus. A reduced amount of saliva, found in most of these patents, can lead to an impaired capacity for buffering in the stomach, leading to gastritis or oesophagitis. A symptom description might go like this:

I need to drink at night. When I wake up in the morning, I feel like I have had a ball in my mouth – a thick ball – and I think: “Thank God – It's a miracle that I was able to breathe last night!” (our translation)¹⁹

- Dichotomies or gradual transitions – signs of different validity?

Clearly demarcated biomedical findings, representing a deviation from what is regarded as normal, are the basic schemata for the doctor to interpret symptoms. Deviation represents pathology – the more conspicuous the deviation, the stronger the possibility that the patient is sick. It appears to be especially difficult for the doctor as well as for the patient, and the environment to create an analytic distance from symptoms which are closely related to phenomena of everyday life and which embody phenomena we have all experienced. A woman with low back pain in her third pregnancy looks back on her first pregnancy:

At that time we still led an active life, hiking, dancing, and doing many other things which my husband did not accept that I could no longer continue and which he did not quite understand. When I asked him to turn back on a walk, since we still had to go all the way home, he ... he did not quite accept that it was time to turn round. So I guess I pushed my limits too much in many situations [...] so I would not appear as a whimpering woman. Why should I get special attention? (our translation)²⁰

Patients with chronic fatigue syndrome present symptoms of a different degree and character from those associated with the weariness of everyday life.²¹ They experience fatigue which would be characterised as both extreme and abnormal, mentally as well as physically, compared to the more banal exhaustion of everyday life:

It feels like I am waking up with the flu every morning; it's a fight to get out of bed. Irrespective of how much I sleep, I don't get any better. Consequently, I stay in bed, often for several days. When I am able to get up, it's too demanding for me even to shower or eat ... (our translation)

Doctors also experience stomach pain, headache, muscular pain, fatigue or depressed moods. Since the medically unexplained disorders often consist of exactly these kind of symptoms, the doctor may erroneously believe that he or she knows what it is like and therefore not acknowledge the patient's illness experience. These symptoms are not easy to distinguish, clarify, or categorise within biomedical schemata. It is easier to perceive signs of demarcation than signs of range, since schemata applied for biomedical purposes assume that there are definite distinctions between sick and healthy.

But how do we distinguish between a headache as an ailment of everyday life and a headache as disease?²² One plausible answer is that the borderline between normality and pathology depends on how often and how strongly the symptoms emerge. Anyone can have a headache

from time to time, but repeated episodes several times a week might be regarded as an illness. Another distinction between everyday ailments and disease relates to the way in which the affected individual copes with his or her headache. The doctor might have different resources for coping in his or her life from the patient, and thereby confuse the degree of seriousness of symptoms which appear to be recognisable with the doctor's own perception of the ailment.

WHAT MIGHT HAPPEN?

Clinical discourse involves more than the exchange of information. Studying interactions related to different spaces for reflection, we observed various outcomes and foci related to objectification. We found that assumptions could be shared between patient and doctor, even when symptoms were not clearly delineated. Under other conditions, the patient might be dismissed from the reflective space, or even become the target of objectification.

- Sharing assumptions through successful objectification

Some conditions allow patient and doctor to meet in a shared space for reflection where both can use a biomedical model of representation to objectify the symptoms presented. This will typically happen when objective findings confirm the patient's story, support the doctor's acknowledgement of the patient and her symptom experience, and provide the direction for treatment or further investigation. In such cases, the patient also wishes to feel included and to attend to the process – as reported by a woman describing a pelvic examination:²³

Yes, it gives me reassurance knowing there is nothing wrong – especially if tests are done. Many diseases might be free of symptoms – you can become sterile without knowing it. (our translation)

Sharing assumptions can also lead to the successful objectifying of less distinct symptoms. In a treatment program for women with chronic pain, participants emphasised the importance of getting an acceptable explanation for their problems:²⁴

The information we have been given – when we've had time to think about it in between giving all these life histories – has been very important to me: to have some explanations! (our translation)

- Dismissing the patient from the space for reflection

Symptoms in patients with MUD often seem to challenge established medical categories and distinctions, and thereby indirectly the doctor's professional authority. Findings from our studies indicate that the focus of objectification in such situations may be shifted from the complaint to the patient.²⁵ Patients with chronic fatigue syndrome stated that their doctor's interest decreased when their condition did not improve.²⁶ A patient quotes her doctor:

I won't deny that you would have been much more interesting to me if you had been suffering from a cardiac disease ... (our translation)

Women patients report that they feel categorised by the doctor as “stressed menopausal housewives” when the medical gaze can find nothing wrong. The biomedical judgment (“no

objective finding”) interacts with a cultural stereotype (“stressed menopausal housewife”) in such a way that the incongruity of explanations legitimates the dismissal of the patient’s opinions. *Biased objectifying* can occur when the doctor further delineates and characterises the patient, as opposed to a process where patient and doctor jointly negotiate the possibilities of meaningful interpretation of the patient’s symptoms. Patients will often perceive such rejection as threatening, and try to maintain their position in a previously shared reflective space by insisting on being referred for further investigation. Although both sides still adhere to the biomedical model of representation, the doctor has concluded that there is in fact nothing wrong with the patient.

- Diagnosing the patient’s credibility

When the doctor assumes that the patient is not “really” ill, biomedical understanding can still be extended by pursuing the classical medical path.²⁷ Further examinations will have a potential double meaning: on the one hand, they might provide medical evidence, but on the other, they become a means of assessing the patient’s credibility. A woman with chronic pain stated:

I had been to a tanning salon. I hadn’t remembered that I was going to visit the doctor the following day...and I actually did look pretty healthy. And when I arrived, he [the doctor] remembered the letter I had sent him about my pain, and said: “You’re not ill!” I didn’t answer – because what could I say? After a while he said: “You certainly don’t look ill!” (our translation)²⁸

Two different schemata can be used by the doctor to interpret patients’ symptom presentations: to be interpreted either as information about the *symptoms* (she has her complaint, and together we can explore it), or as information about the *patient* (she *is* her complaint, and the doctor can explore her and categorise her). In the first of these schemata, the symptoms are objectified within a shared space for reflection, while in the second the *patient* is objectified and thereby dismissed from the reflective space as if she were an intruder. The doctor’s reluctance to acknowledge symptoms which appear medically unexplained can contaminate other problems, disturb the focus of objectification and reflection, and become a medical burden for the patient.

The doctor’s assessment of the patient’s credibility is seldom expressed explicitly, but may function as a tacit rule in the rhetorical space created. The patient can experience this as subtle suspiciousness on the doctor’s part. It then becomes important for the patient to convince the doctor of her own dignity, a project which the doctor may well perceive as merely irrelevant and annoying talk.

When the patient’s credibility is questioned in this way, the focus of objectification is already in the process of shifting from complaint to patient. This will often interact with and increase the patient’s feeling of responsibility for her own health, closely related to guilt.²⁹ Pregnant women with pelvic or back pain can reproach themselves for being in pain:

What did I do to get like this? (our translation)³⁰

DISCUSSION

Above, we have presented our analysis of the conditions for acknowledging the symptom descriptions offered by patients as sources of medical knowledge. We have argued that spaces for reflection which can be shared by doctor and patient can make for constructive discourse, allowing apparently unexplained disorders to be negotiated and decoded. Below, we elaborate on the impact of cultural barriers that obstruct such processes, and we contrast these with examples of successful transformative action where alternative discourses can be created.

CULTURAL BARRIERS THAT CLOSE SPACES FOR REFLECTION

A number of powerful cultural forces will counteract the possibility of establishing spaces for reflection which can be shared by doctor and patient. Our review suggests that these obstacles can be related to notions of time, gender, and shame.

In the biomedical context, symptoms which can be confirmed within the parameters of the medical gaze will signify a cause which can be determined with regard to *temporality* (heredity, accident, infection) with reasonable precision. The symptoms are manifested within a determinable space of time, and variation and consistency in symptom experiences are intelligible because they can be related to datable biomedical events. A number of MUDs, however, challenge this interpretation through the dimension of time itself. What is the relationship between temporality and women's experiences of symptoms and their acknowledgement? Concepts such as "concrete time" (time as perceived and interwoven in the life of the individual) as compared to "abstract time" (the generalised time of the clock) provide different paths to the understanding of chronic yet fluctuating disorders. The possibility of establishing shared spaces for reflection requires a fresh view of the impact of time on health and illness.

Women suffer much more frequently than men from conditions classified as medically unexplained. Women's health complaints are less often investigated and conceptualised than are those presented by men.³¹ The encounter between patient and doctor is one of several cultural arenas for the negotiation, confirmation and production of cultural constructions of *gender*, which for women are represented by cultural expectations and stereotypes of womanliness. Such gendered practices explain how objectifying moves from the female patient's problem to the patient herself. Demarcations between and constructions of autonomy and dependency, subject and object, actor and victim, are the basic foundations of the formation of identity when gender is acknowledged. In other contexts, concepts such as boundlessness and objectification have been used to describe the condition of women's lives. Reflecting upon or objectifying the illimitable, the vague or the changing, and acknowledging this as legitimate sources of knowledge, requires an awareness of the impact of gender on the sense of demarcation.

In Western culture, biomedical conditions regarded as self-inflicted hold a lower status than other disorders. Which symptoms does the doctor (and maybe also the patient) relate to *blame* and responsibility, and under what conditions do these symptoms or the doctor's interpretation of them evoke feelings of blame and shame? Some patients blame themselves

for doing too little exercise, others for taking the wrong kind of exercise, some for being too stressed, and others for having pain thresholds which are too high. To arrive at a healthy state is regarded as an individual achievement. Guilt can easily be transformed into shame when people are confronted with an understanding of self which they cannot accept.³² A number of studies from our network demonstrate the impact of the doctor's acknowledgement of the patient's personal strengths as a potential mechanism for counteracting blame and offering empowerment.³³

The attribution of blame may be an option for the doctor confronted with a weary woman (or man?) who "has let herself – or himself – be overwhelmed" through caring for others – an option not considered in the case of a young man (or young woman?) who presents with problems related to extreme sport activities. What is the connection between responsibility/blame and gender/power when symptoms are interpreted? Perhaps the potency of social structure, gender and class outweigh an open-minded evaluation of symptoms.

TRANSFORMATIVE ACTION – NEW PERSPECTIVES

Thus, while shared spaces for reflection are under serious threat, yet at the same time they are especially significant in encounters with patients with medically unexplained disorders. What options are available to the doctor who faces the insufficiency of traditional analytic strategies in the case of patients with MUD? In recent decades, the patient-centered clinical method has become a strong foundation of general practice. According to this method, the illness agenda of the patient is explored simultaneously with the disease agenda of the doctor in order to create common ground for understanding and management.³⁴ While such approaches are necessary, they do not constitute sufficient conditions for creating alternative spaces for reflection.

In "Symptoms as a Source of Knowledge", we aimed to legitimise the experiences of the patient. To make this goal a reality, we developed a number of tools to facilitate the development of what we here have called "spaces for reflection", which can be shared by doctor and patient. In some of the projects we explored, systematised, and conceptualised the description of symptoms in various MUDs in order to facilitate objectifying of the complaint rather than the patient. In these projects, we have sought to contribute to the creation of a more accurate map of clinical disorders by developing better abstractions.³⁵

In other projects, we have developed methods whereby the doctor elicits the individual patient's voice and experiences in order to make them a part of the development of clinical knowledge. These projects concentrate on patients' self-assessed personal health resources,³⁶ doctors' acknowledgement of their patients³⁷ and the elaboration of new dialogues.³⁸

Strategies which recognise patients' voice and symptoms as legitimate and useful sources of knowledge will cast doubt on the established authority of the medical gaze. According to the biomedical representational model, the proper use of available and valid sources of medical knowledge will usually provide the answer to the question of what causes the patient's problem. This model is assumed to work, regardless of whether or not the doctor learns something new in the process. To acknowledge the patient's symptoms, even when these contradict the medical gaze, implies that there is something the doctor can learn in

his or her interaction with an individual patient. If so, the clinical encounter can be compared to action research, where knowledge and action are developed together, intertwined with experience, in contrast to the traditional scientific approach where the object of study is put under the lens and observed through the gaze of the researcher.³⁹

SURPRISE AND CURIOSITY

We have criticised the shortcomings of the biomedical model of understanding illness, illustrated by medically unexplained disorders. Our critique does not imply that doctors always prefer the biomedical perspective. We would rather warn against the premature conclusion that doctors will inevitably resist the prospect of abandoning control over the consultation.

Perhaps a more adequate explanation is that medical practice lacks traditions and methods for objectifying the patient's symptoms in a shared space for reflection. In our project, we have seen how the doctors' point of view can be radically changed when the patient demonstrates unexpected strengths and a surprising capacity to initiate action strategies.⁴⁰ We know from experience that curiosity and surprise can be powerful spurs for enthusiasm, motivation and change. In future research, this idea could be pursued by exploring how doctors might experience positive challenges through questioning their own powers of definition and do not take the traditional analytic models for granted. Establishing new spaces for reflection could generate strength and recognition for male as well as female patients, and also provide the doctor with new and useful knowledge.

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