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Chapter

4

*Explanations for medically
unexplained symptoms: a
qualitative study on GPs in daily
practice consultations*

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Abstract

Background: General practice is the centre of care for patients with medically unexplained symptoms (MUS). Providing explanations for MUS, i.e. making sense of symptoms, is considered to be an important part of care for MUS patients. However, little is known how general practitioners (GPs) do this in daily practice.

Objective: This study aimed to explore how GPs explain MUS to their patients during daily general practice consultations.

Methods: A thematic content analysis was performed of how GPs explained MUS to their patients based on 39 general practice consultations involving patients with MUS.

Results: GP provided explanations in nearly all consultations with MUS patients. Seven categories of explanation components emerged from the data: defining symptoms, stating causality, mentioning contributing factors, describing mechanisms, excluding explanations, discussing the severity of symptoms and normalizing symptoms. No pattern of how GPs constructed explanations with the various categories was observed. In general, explanations were communicated as a possibility and in a patient-specific way; however, they were not very detailed.

Conclusion: Although explanations for MUS are provided in most MUS consultations, there seems room for improving the explanations given in these consultations. Further studies on the effectiveness of explanations and on the interaction between patients and GP in constructing these explanations are required in order to make MUS explanations more suitable in daily primary care practice.

Background

Medically unexplained symptoms (MUS) are somatic symptoms that doctors cannot attribute to a clear organic cause¹. MUS are often associated with functional impairment^{2,3}. In general practice, about 3–20% of all consultations concerns patients with MUS⁴⁻⁷.

The central location of care for patients with MUS is general practice⁸⁻¹⁰. Moreover, general practitioners (GPs) themselves claim this central position and indicate that they should remain the central person in managing patients with MUS¹¹. However, GPs often feel uncomfortable with this care, as they experience patients with MUS as difficult¹⁰⁻¹⁵. A review of 13 qualitative studies on the management of MUS in primary care reported that there is incongruence between the ideal disease model and the reality of meeting patients who do not fit in this biomedical disease model¹⁶. Explanations, i.e. how GPs make sense of patients' symptoms in the context of patients' lives, are thought to be crucial to overcome this incongruence¹⁶.

The explanation of symptoms to patients is a substantial and important part of the consultation. This certainly is the case in MUS consultations¹⁷, although GPs experience many difficulties here because causes for MUS are not fully understood. A Dutch study reported that, in MUS consultations, approximately a fifth of the consultation time is spent on explanations¹⁸. Besides, explanations help patients to understand the connection between their psychosocial life and physical symptoms¹⁹, prevent unnecessary diagnostic and potentially harmful testing²⁰, and form a valuable foundation on which recovery of patients is built²¹.

In the scientific literature, there is a large body of knowledge on the characteristics of effective explanations. Patients accept empowering explanations, i.e. explanations that provide patients with the opportunities to manage the symptoms themselves. Besides, patients value normalization of symptoms when such an explanation is plausible, blame-free, and facilitates the therapeutic relationship²¹. Multiple explanatory models for MUS have been described in the literature²². However, this scientific knowledge does not seem to translate into daily clinical practice, since GPs still experience problems in explaining MUS to patients¹⁸. This leads to the question how GPs construct their explanations for MUS in daily practice. Most research on this topic is based on indirect accounts of consultations, such as focus groups and interviews¹⁶.

The scarce studies exploring the way GPs build explanation in MUS consultations in daily primary care practice took place in a specialized care setting (i.e. patients referred to a symptoms clinic with trained GPs) or focussed on a single specific explanation (i.e. nor-

malization) ^{23–25}. Therefore, it remains largely unknown how GPs do this in daily general practice consultations. Insight in the content and construct of these explanations may guide improvements of GPs' explanations and, thereby, quality of care for patients with MUS. Therefore, the aim of this study is to explore and describe how GPs explain MUS to their patients during daily general practice consultations.

Methods

We performed a qualitative study in which we analysed transcripts of video-recorded consultations between GPs and patients with MUS in daily general practice. We choose thematic content analysis as research method, as we were interested in unravelling the explaining process. Thematic content analysis is a research method for subjective interpretation of the content of text data, which is done by the systematic classification process of coding and identifying themes ²⁶.

Sample

Video-recorded consultations and their verbatim transcripts were collected in the course of the Clinical Assessment as Therapy in managing Medically Unexplained Symptoms project (CATMUS) ²⁷. One of the researchers (ToH, a senior GP) approached GPs in the region of Nijmegen, the Netherlands, to participate. We used purposive sampling to ensure variety among participating GPs in terms of age, sex, working experience, and geographical location (city versus rural area). The approached GPs varied in their experience with MUS. Thirty-six GPs were approached, of whom 20 participated. When GPs agreed to participate, one of the researchers (JH, a GP trainee) visited the practice. Participating GPs were informed that this study concerned communication in general consultations between GP and patient.

Data were collected in 2015 from April to September. JH invited all patients, aged 18 years or older who spoke Dutch fluently, in the waiting room of the primary care practices to participate. Patients were informed that the study concerned communication between GP and patient, without mentioning the special interest in MUS. Of 509 eligible patients, 393 agreed to participate in this study (77%). No researchers were present during consultations, as the consultations were video-recorded.

GPs defined whether a consultation concerned MUS. Immediately after the consultation, the GP answered the following question on a three-point scale (MUS, partial MUS and medically explained symptoms): 'Do you think this patient has MUS considering his/her

physical symptom presentation?’ This method ensured that we observed GPs dealing with what they perceived as MUS. The GP’s opinion to identify whether a consultation concerned MUS is also used in previous research^{20,28}. We analysed all MUS consultations (partial MUS consultations were excluded): 39 consultations with 39 unique patients and 18 GPs (Tables 1 and 2). We expected our sample to be sufficient for an in-depth exploration of GPs’ explanations for MUS^{15,18}.

Table 1 Characteristics of the 18 participating GPs, 2015, the Netherlands.

| | |
|--|------------|
| Age in years [mean (min–max)] | 46 (31–69) |
| Sex (<i>n</i>) | |
| Female | 9 (50%) |
| Male | 9 (50%) |
| Working experience in years [mean (min–max)] | 15 (2–43) |
| Geographical location of practice (<i>n</i>) | |
| City | 8 (44%) |
| Rural | 10 (56%) |

Table 2 Characteristics of the 39 participating patients with medically unexplained symptoms, 2015, the Netherlands.

| | |
|--|------------|
| Age in years [mean (min–max)] | 53 (19–88) |
| Sex (<i>n</i>) | |
| Male | 11 (28%) |
| Female | 28 (72%) |
| Level of education ^a (<i>n</i>) | |
| Low | 5 (13%) |
| Medium | 22 (56%) |
| High | 12 (31%) |
| Voluntary or paid work (<i>n</i>) | |
| Yes | 17 (44%) |
| No | 22 (56%) |

Analysis

We started with reading each transcript line by line while coding in Atlas.ti-7 all text fragments in which the GP made sense of the patient’s symptoms. Following Morton et al., we defined an explanation as follows: ‘a sequence of utterances by the doctor (with or without input from the patient) which began at the point a GP introduced an explanation of how the patient’s symptoms might be understood and ended when the conversation moved to another aspect of the consultation’²⁴. This first coding of text fragments was performed independently by TT and JG. If necessary, agreement was sought after coding each consultation. Coding was performed using Atlas.ti-7. Our objective was to explore the construct

of the explanations GPs provided. In order to do so, we aimed to identify the smallest units from which explanations are built (i.e. 'Components') and to come to themes of components (i.e. 'Component categories'). To allow new insights to emerge and to come to an inductive category development, TT and JG read first all explanation quotations several times to familiarize themselves with the quotations and then made a One Sheet Of Paper (OSOP) analysis. OSOP analysis is a way of visually rearranging the extracted data in order to define categories or themes²⁹. We wrote the explanation quotations down on a single sheet of paper, which enabled us to look clearly for similarities and differences in the data. Besides, we looked closely how GPs constructed their explanations, in terms of component use as well as language use. Memos were prepared during this process. Subsequently, a refining of the coding was done by the first author in close consultation with the second author by breaking the explanations quotations in Atlas. ti-7 into various components, coding them and comparing those with other components from other explanations. TT and JG discussed their insights and findings in regular discussion sessions with senior researchers ToH, PL, JR and MB. This analysis continued until all components of GPs' explanations were captured in various component categories. Saturation in terms of component categories was reached after analysing 28 consultations. That is, in the last 11 consultations, no new component categories emerged from the data.

Results

In 36 of the 39 consultations, GPs provided patients with MUS with an explanation of how their symptoms might be understood. In total, we observed 41 explanations as in 5 consultations, GPs provided explanations for two independent symptoms. Within these 41 explanations, we identified 174 explanation components that could be summarized into 7 component categories. Before describing the component categories in detail, three general aspects on how GPs made sense of patients' symptoms are worth mentioning. First, most explanations were not very detailed. Explanations regularly consisted of no more than two or three sentences. Second, when explaining symptoms, GPs usually communicated this as a possibility, as they used words that expressed uncertainty such as 'could', 'might', 'perhaps' or 'unsure'. Although we noticed some explanations that were stated firmly by the GP, in general, GPs were cautious in stating how symptoms might be understood. Third, most explanations were patient specific, meaning that the GPs often tailored their explanations to the specific situation of the patient, instead of speaking of how symptoms might be understood in general terms. A representative explanation follows:

Consultation #39

'I can't really say there's much wrong. It all looks fine on the outside.

Well, it's probably nothing really serious...'

'...then it really is something very subtle in the foot ... because then it must be to do with how it's used, how you move and so on.'

'It could easily be the case, for example, that you had a slight injury once...'

'...and since then you've always kept moving slightly wrong, or something like that'.

Components of MUS explanations

Seven categories of explanation components emerged from the data: redefining the symptoms, stating causality, mentioning contributing factors, describing mechanisms, excluding explanations, discussing the severity of symptoms and normalization. We observed large differences between explanations in terms of the number of components, the combinations of component categories and the order of component categories GPs used to build the explanations. In Table 3, we provided an overview of all components

we observed in GPs' explanations. Although the component categories seem to be distinct entities, we have observed that the categories show (partial) overlap and that GPs were combining categories in the consultations. Therefore, we grouped these seven categories by its function: (i) invoking cause, (ii) neutral approach and (iii) excluding alarming disease.

Table 3 Component use by GPs in constructing explanations for MUS, 2015, the Netherlands.

| CONSULTATION # | Component categories | | | | | | |
|----------------|----------------------|-------------------|---------------------------------|-----------------------|------------------------|-------------------------------------|----------------------|
| | Neutral approach | | Invoking cause | | | Excluding alarming disease | |
| | Defining symptoms | Stating causality | Mentioning contributing factors | Describing mechanisms | Excluding explanations | Discussing the severity of symptoms | Normalizing symptoms |
| 1 | •• | ••• | • | • | • | •• | • |
| 2 | | | • | | • | | |
| 3 | | | • | | | | |
| 4 | | ••• | | | • | | |
| (5) | | | | | | | |
| 6 | • | | | | | | |
| 7 | •• | | • | •• | •• | • | |
| 8 | •• | | • | • | • | • | |
| 9 | | | | | • | • | |
| (10) | | | | | | | |
| 11 | • | ••• | • | | • | • | |
| 12a | | | | | • | | |
| 12b | • | | •• | | | •• | |
| 13 | | | | | • | | |
| 14 | • | | •• | •• | • | • | • |
| 15 | | | • | | | | |
| 16 | • | | | • | | | |
| 17 | • | •• | | | | • | |
| 18a | • | | | | | | |
| 18b | | | | | • | | |
| 19a | | | | | | • | |
| 19b | • | | | | •• | | |
| 20 | •• | | | | | | |
| 21 | • | • | •••• | • | •• | • | |
| 22 | ••• | ••• | | •• | ••• | | |
| 23 | • | | • | | | | |
| 24 | • | •• | | ••• | •• | • | |
| (25) | | | | | | | |
| 26 | • | | | •• | | | |
| 27a | • | | •••• | | | •• | |
| 27b | | | | | •• | | |
| 28 | •• | •• | | | ••• | • | |
| 29 | •••• | • | | | | | |
| 30 | | • | | | | • | |
| 31 | ••• | | | | • | • | |
| 32a | •• | | •• | | • | | |
| 32b | • | | | • | | | |
| 33 | | • | | | | | |
| 34 | • | | • | •• | • | •• | • |
| 35 | • | | | •• | | | |
| 36 | | | | • | | | |
| 37 | •• | | | | | • | |
| 38 | | •• | | • | • | • | • |
| 39 | • | • | • | | | • | |

• = a single explanation component (for instance, in consultation #4 the GP mentioned three different (possible) causes for the patient's symptom, alongside one excluding explanation).
 (#) = a consultation without explanation components/an explanation.
 12a = the first explanation of consultation 12.
 12b = the second explanation of consultation 12.

Components of MUS explanations—neutral approach

● *Defining symptoms*

In a majority of explanations, GPs made sense of symptoms by naming the symptoms. GPs gave definitions of the patients' symptoms using phrases like 'You have X' or 'The problem is Y'. We found there are three ways GPs defined patients' symptoms. First, GPs used layman's terms to name symptoms. This kind of naming was observed most frequently. For example, GPs told patients that they had a lump in the throat, irritable bowels, a cramping muscle and an irritated/overloaded (shoulder) tendon. Second, they used medical terminology, such as fibromyalgia, a dissociative disorder and a non-typical allergy. Third, in a couple of explanations, GPs redefined symptoms by localizing the symptoms, i.e. GPs solely referred to a patient's body part: 'I think it's the ribs' or, in another explanation, 'Your stomach ache is merely your large intestine'.

Components of MUS explanations—invoking cause

● *Stating causality*

GPs frequently stated causality between a certain factor, such as 'heavy work', and the patients' symptoms. We found that GPs used four subgroups of causes. First, in several explanations, GPs mentioned continuing causes: constant factors that are assumed to keep causing the symptoms. For instance, a GP told his patient: 'that has to do with the fact that your stomach is somewhat opened at the top end' as a continuing cause for burping. Second, GPs mentioned triggering events, i.e. event that occurred at one moment in time that triggered the symptoms. GPs in our study mentioned several triggering events, such as a fall that caused shoulder pain, an inflammation that started fibromyalgia and a wrong sleeping position that caused pain on the chest. Third, in a few explanations, GPs mentioned factors that increased the risk for developing symptoms. A patient with back pain was told: 'You have a small bend in your spinal column, did you know that? It could have contributed to the start of your pain ... this bend didn't occur recently, you have had this for years'. Fourth, in two explanations, the GPs stated that they did not know what the cause of the symptom was, nevertheless confirming that there was a cause. Noteworthy, in one explanation, a GP mentioned that a cause was not necessarily present when a patient had symptoms, by which he denied causality rather than stating it.

● *Mentioning contributing factors*

GPs mentioned factors that play a role in aggravating or perpetuating the symptoms without stating that these factors caused the symptoms. We observed contributing factors in nearly half of all explanations. Examples are ‘fatigue can also play a role’ or ‘that you are so worried also has to do with it’ or ‘the amount of burden varies, that depends on how much stomach acid your body produces, or whether you are stressed, or on what kind of food you eat, those sorts of things’. Contributing factors are not related to the start of the symptoms.

● *Describing mechanisms*

A mechanism is a description of a process how symptoms occurred at the very moment. In a mechanism, GPs mentioned how certain components (i.e. definitions of symptoms, causes or contributing factors) are linked to the symptoms. For example, a GP had defined the patient’s symptom of feeling short of breath as ‘a lump in your throat’, but this definition did not explain why this patient was short of breath, which was her main symptom. The GPs described the process of having symptoms, linking the definition to the symptom, in the following mechanism: ‘it could very well be that the muscles surrounding your Adam’s apple completely cramped, which gives your symptoms. And we call that a lump in the throat’. In two explanations, we noticed a special kind of mechanism, namely the vicious circle: ‘What happens is that you end up in this kind of circle. You are worried about your shortness of breath, and that gives even more tension form the inside’.

Components of MUS explanations—excluding alarming disease

● *Excluding explanations*

This component category is unique in the way that GPs made sense of symptoms by mentioning factors that were not related to the symptoms. GPs did this in the majority of explanations. Mostly, excluding explanations concerned medical terminology or a certain body part of which the GP stated that it had nothing to do with the symptoms, such as ‘I’m not afraid of a stroke or a brain tumour’ or ‘actually, there can’t be a hernia’ or ‘your lungs are fine, there is nothing wrong there’.

● *Discussing the severity of symptoms*

In several explanations, GPs discussed the severity of the patients’ symptoms by mentioning the seriousness of the symptoms, giving prognoses for the symptoms and stating possible consequences of the symptoms. GPs mentioning how serious the symptoms should

be considered was observed most frequently. For example, ‘Luckily, I don’t hear alarming things in your story’ or ‘listening to your symptoms, I’m not actually worried’. Regularly, GPs spoke of patients’ symptoms as not severe or only a little severe.

● *Normalizing symptoms*

In a couple of explanations, GPs normalized the patients’ symptoms. On the one hand, GPs emphasized that symptoms are ‘normal’: ‘you have had these symptoms for years, it’s probably something that is a part of you’. On the other hand, GPs focussed on the absence of apparent disease: ‘you are completely healthy, I really can’t find anything (of that sort)’.

Conclusions

Summary of main findings

GPs provide explanations for MUS in nearly all consultations with MUS patients. We found seven categories of explanation components: defining symptoms, stating causality, mentioning contributing factors, describing mechanisms, excluding explanations, discussing the severity of symptoms and normalizing symptoms. No pattern of how GPs constructed explanations was observed as the number, the combinations and the order of used components varied widely. GPs usually provided short explanations that were not very detailed. Furthermore, the majority of explanations were communicated as a possibility and in a patient-specific way.

Strengths and limitations

This study addressed explanations for MUS in clinical practice through studying general practice consultations. The observational study design provided a picture of how GPs explain MUS during daily practice in contrast to focus group and interview studies that provide information about how GPs report to explain MUS¹⁹.

A possible limitation could be a variation of selecting patients with MUS by the participating GPs, resulting in a heterogenic group of MUS patients. As our aim was to identify how GPs explain MUS, ensuring that we observed explanations for what GPs perceived as MUS was considered to be more important than a possible interdoctor variation in the selection of MUS patients.

A limitation of this study is that we observed only one consultation per patient. Therefore, we cannot evaluate the quality or the completeness of the observed explanations, as explai-

ning symptoms is a process that may take several consultations. Nevertheless, this study is appropriate for describing the variability of how GPs provide explanations in daily practice, as our sample included first consultations as well as follow-up consultations of various patients and GPs. Moreover, saturation in terms of explanation components was reached in our sample, as no new categories of explanation components emerged in the last 11 consultations. It is worth noting that most of the observed MUS consultations concerned mild to moderate severe MUS in the daily primary care practice. It could be that in severe MUS, GPs use other ways of explaining MUS, but that is beyond the scope of this study. Finally, a possible limitation of this study is the altered communication between doctor and patient due to the consultations being video-recorded. However, earlier studies did not show significant behavioural changes associated with video recordings³⁰⁻³². Referring to the CATMUS project, most doctors claimed they experienced no problems in ignoring the camera, and most patients said they did not notice a change in the behaviour of their GP²⁷.

Comparison with literature

In general, we observed explanations that were short, patient specific and that were communicated as a possibility. In contrast, an earlier study based on consultations in a specialized MUS clinic found extensive explanations that were communicated both in general terms as well as patient-specific ways^{23,24}. This difference might be explained by the differences in setting since we based our study on consultations in general practice, while their sample consisted of trained GPs and patients with multiple and/or persistent MUS that had been referred to a specialized clinic.

Another interesting discrepancy with the literature is the use of explanatory models, characterized by complicated pathophysiological mechanisms. These were often seen in the study of Morton et al.²⁴ and are well known in the scientific literature²². However, the explanations in our study were more superficial, meaning that GPs did not elaborate on such pathophysiological mechanisms. We only observed a few GPs who briefly discussed the explanatory models of sensitization and sensitivity. The use of explanatory models might become more relevant if the symptoms are more severe or persistent as was the case in the study of Morton et al.²⁴.

Our finding on GPs communicating explanations as a possibility seems in line with previous research on GPs experiencing difficulties to explain the nature of the symptoms¹⁹. However, this could also be due to the process of building an explanation together with the patient, the delicacy of finding common ground and the uncertainty about MUS in general.

In a focus group study, GPs reported to explain symptoms in three ways: telling patients there is no disease, normalizing symptoms by telling that it is normal to have symptoms

and using metaphors to give patients some insight in the hypothesized interactions between symptoms and psychosocial life ¹⁹. In this study, we did observe GPs normalizing symptoms in a couple of explanations, although we hardly noticed GPs using metaphors. Furthermore, we rarely observed GPs who told patients explicitly that they had no disease. In conclusion, our study suggests there are remarkable differences between what GPs say they do and what GPs actually do.

Finally, we did not notice reattribution of the complaints by the GPs. From studies, it is known that reattribution is not helpful for MUS ³³, so it is interesting that Dutch GPs apparently do not use this (anymore).

Implications for practice and future research

In this study, we described in detail the content of GPs' explanations for MUS in daily practice. However, the quality or effectiveness of an explanation does not solely depend on the content of the explanation. Various studies report on the importance of the interaction between doctor and patient in formulating an explanation. Explanations are stated to be crucial to overcome the incongruence between doctor and patient, but asserting only professional models and not considering the patient's models or illness representations may instead maintain incongruence ¹⁶. In other words, the ability of an explanation to satisfy patient and doctor depends on a delicate process of negotiation, which requires dialogue ³⁴. We did not include the interaction between doctor and patient in this study, but we would welcome future studies on how this interaction, and its characteristics such as gender, influence how MUS are explained to patients. Besides, we would welcome future studies on which (combinations of) components of explanations are most effective and acceptable in daily general practice.

Declarations

This study is supported by ZonMw (839110010). The Research Ethics Committee of the Radboud University Nijmegen Medical Center concluded that the study could be carried out (2015-1566). Written informed consent was obtained from all participating patients; patients were able to withdraw their consent at any time.

