

## Research Article

# Patients' Perspectives On Improvement Of Medically Unexplained Physical Symptoms: a Qualitative Analysis

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## ABSTRACT

**Title:** Patients' perspectives on improvement of Medically Unexplained Physical Symptoms: a qualitative analysis.

**Background:** Medically unexplained physical symptoms (MUPS) are common. Knowledge of factors contributing to improvement of MUPS may be useful for the development of more effective treatments. This study aims to assess the factors contributing to improvement of symptoms, according to recently improved MUPS patients.

**Methods:** This qualitative study is part of a prospective cohort study on the course of MUPS. We selected patients with at least moderate MUPS at baseline and with a substantial decrease of symptoms after 6 or 12 months. We performed semi-structured interviews. Recordings were transcribed verbatim and analysed in ATLAS.ti.

**Findings:** Although saturation of data was reached after 6 interviews, 9 patients were interviewed. Their symptoms had developed gradually and worsened until a certain point of crisis. Before this crisis patients were focused on finding symptom causes and on becoming one's old self again. The experience of a crisis made them accept their situation. This resulted in a search for improvement instead of recovery. Participants started

taking control of their own well-being by coping differently (e.g. by pacing activities and relaxing effectively), mostly supported by a therapist. This led to symptom improvement.

Participants deemed it important that General Practitioners and therapists were coaching and took their problem seriously. Received therapies varied from regular therapies to complementary therapies. The latter were experienced as effective, as they combined psychological and physical components. Some participants missed this multidimensional approach in regular treatments.

**Conclusions:** Acceptance of symptoms and their consequences seems to be the most important condition for improvement of MUPS. As a moment of personal crisis forms the most important motivation for acceptance, it may be something that cannot be forced by therapists. Nevertheless, General Practitioners and therapists can support patients on their way to acceptance. A wish for multidimensional treatments in regular health care was identified.

**MeSH Headings/Keywords:** Somatoform Disorders, Psychological Adaptation, Illness behaviour, Sick Role, Primary Health Care

## Introduction

**MUPS:** In all health care settings patients present with physical symptoms for which no sufficient somatic explanation is found after proper medical examination. We call such symptoms medically unexplained physical symptoms (MUPS). Around 20-30% of MUPS patients in primary care develop persistent MUPS, which can be severe and disabling [1,2]. Patients with persistent MUPS have a greater risk of psychosocial disability and experience more psychological distress than patients with explained physical symptoms [3].

Most MUPS treatments focus on illness thoughts and behaviours and aim to control perpetuating factors. However, the effect of these treatments is limited [4]. This may be due to the fact that knowledge of which factors aggravate or mitigate the course of MUPS is scarce.

**Predisposing and perpetuating factors:** Several studies on the course of MUPS have been performed. However, results are conflicting and methodologies and outcome measures are heterogeneous [5]. In theoretical literature the cognitive behavioural model is seen as a meta-model, which incorporates many theories of mechanisms influencing MUPS [6]. This model incorporates different domains, including somatic causes, illness predispositions, perceptions, behaviours, emotions and social factors. A narrative review showed some evidence for the presence and influence of these elements [7]. However, it is unknown which elements play the most important role in the persistence and improvement of MUPS.

**Patients' perspectives:** Better insight in factors contributing to improvement of MUPS is essential to guide development of more effective treatments. As described above, most research addresses this topic from an epidemiological or theoretical perspective. We believe that an additional focus on patients' perspectives is essential, as patients are experts by experience. Patients whose symptoms have improved may provide important clues, as they apparently managed to control their symptoms. Therefore, this study aimed to assess the factors contributing to improvement of symptoms, according to MUPS patients who recently improved.

## Methods

**Population:** This qualitative study was part of the PROSPECTS study, a multicenter prospective 3-year cohort study on the course of MUPS. In this study MUPS patients were included in general practices (239 patients) and in specialized MUPS programmes of secondary and tertiary care organizations (114 patients). In primary care patients at risk for MUPS were selected using an electronic database search (step 1). Selected patients were screened for MUPS and exclusion criteria by their General Practitioner (GP, step 2) and they were asked to complete a symptom severity questionnaire (step 3) to make sure that they currently suffered from at least one physical symptom which was bothering them a lot.

In secondary and tertiary care organizations, all newly referred patients with MUPS as the reason for referral were screened for in- and exclusion criteria by the physician performing the intake consultation (step 1) and they were also asked to complete the symptom severity questionnaire (step

2). Eligible patients signed informed consent and completed questionnaires at baseline (T0), after 6 months (T1) and after 12 months (T2), and will complete questionnaires after 24 months (T3) and 36 months (T4). The questionnaires included questions about symptom severity, functional impairment and change of symptoms and well-being [8].

**Selection:** For this qualitative study we selected patients who suffered from at least moderate MUPS at baseline, and whose symptoms had improved during follow-up. As the date of inclusion varied among participants, we selected patients whose symptoms had improved after either 6 or after 12 months of follow-up.

We measured severity of MUPS with the Patient Health Questionnaire 15 (PHQ-15) [9], a measure for somatic symptom severity. In the original validation study, a cut-off score of 10 was suggested for detection of moderate MUPS [10], while scores of 5 and lower were correlated with low levels of somatic symptom severity. Therefore, in this qualitative study we used the following inclusion criteria: At T0 patients had to suffer from at least moderate MUPS (reflected by a PHQ-15 score of 10 or higher), This symptom score had to be decreased by at least 5 points according to the last questionnaire (T1 or T2, indicating a significant improvement of somatic symptom severity) and patients had to report subjective improvement of symptoms and/or well-being (according to separate questions about these topics). We purposively selected a study population with variation in gender, age, nature of symptoms and social background. All selected patients provided informed consent.

**Interview:** Two authors (NCvD, FV) performed the interviews together, one being the main interviewer, the other being observant. One of them (NCvD) was trained in qualitative interviewing. Interviews started with an open-ended inquiry. Pace and sequencing of the interview depended on the participant. The interviewer avoided closed questions. Additionally, a topic list was used and checked by the observant during each interview, to make sure that all relevant topics were discussed [Appendix]. This use of a topic list is in line with the framework approach, which aims to evaluate previously developed theories [11].

Interviews were recorded and transcribed verbatim. As qualitative research is an iterative process, the interviewers constantly reviewed the topic list and added relevant topics that had emerged in preceding interviews. The interviewers summarized interviews and summaries were checked for accuracy by the interviewees (member check).

**Analysis of interview transcripts:** After having read the interviews thoroughly, we processed all transcripts using ATLAS.ti (version 7, Scientific Software Development GmbH, Germany). Two authors (NCvD, FV) coded transcripts independently. Codes were compared and discussed, resulting in the development of categories and concepts. Interim findings of the analysis were discussed with two other authors (JCvD, CdB). Data collection continued until saturation was reached. We expected to reach saturation after 10-15 interviews.

**Findings:** All invited patients were willing to participate. During the 6th interview no new items emerged. We performed 3 extra interviews to make sure that saturation was reached.

Six interviews took place at participants' homes, one at a participant's workplace and two at the VU University Medical Center (March–April 2015). Interviews lasted between 45 and 89 minutes. Participants' general characteristics are listed in (Table 1). Seven participants were selected from general practices, 2 were selected from specialized MUPS programs in secondary care settings. Mean interval between completing the last questionnaire (T1 or T2) and interview was 51 days (approximately 7 weeks). Mean PHQ-score at T0 was 16 (range 12–22), mean decrease of PHQ-score at follow-up was 9 points (range 5–16). Nature and severity of symptoms varied widely.

**Development of symptoms:** Most patients described that symptoms developed gradually within a period of months, sometimes years. Only one participant described an acute start of her symptoms (P6).

Looking back, participants stated that many factors played a role in the development of their symptoms. However, most participants described stressful events as the main cause: either work related (e.g. working under difficult circumstances (P3, P4, P6–P8)) or personal (e.g. death of a close relative (P2, P5, P8)).

Quote (P7): It just made sense to me. All the things that I went through... At a certain point it made me lose track... It made me think: how do I deal with this situation? It did not happen as consciously as I describe it now, but... You feel overcome with the situation, and you just keep going on. At a certain point your body gives you signals, and then you think: hang on now, this is the limit... And that is when the symptoms start.

Personality aspects also played a role. Most participants described themselves as caring, hard workers and perfectionists. Their character resulted in a low priority of own well-being. In retrospect most patients thought that their initial coping styles were ineffective. As a result symptoms worsened (P1, P2, P4–P6, P8, P9).

**Crisis and turning-point:** In response to questions about the course of symptoms all participants described a certain moment of crisis. Some described a specific day, others a longer period. During this crisis, symptoms were at their worst.

Quote (P2): A certain day, I was lying on the couch and I knew I had to come off, but I couldn't. I stood up and the nervousness and tension literally made me gag. I had no energy left. I felt breathless after the smallest activity.

This crisis formed an important moment, as participants realized that they did not want to continue going on the way they did. Most of them decided to search for help (mainly by consulting their general practitioner (GP) directly after their experience of crisis (P1, P2, P4–P9)).

Quote (P4): And after 3 months I went completely mad. I got up in the morning and had 2 options: turn left for the railway, or right for the general practitioner.

All GPs offered therapies to the participants. Most GPs had offered therapies before, but at this moment of crisis participants were more open to them, as their crisis activated a strong motivation for change.

**Acceptance of symptoms:** Before the moment of crisis

patients were focused on finding the cause of their symptoms and on becoming one's old self again. The experience of a crisis made it easier to let go of their old situation, accept the new situation and to start searching for improvement instead of recovery

Quote (P5): And at that morning (after the moment of crisis) I woke up and I felt like: and now I am done with it! I've had enough. I accepted the situation, stopped feeling sorry for myself and decided to get a grip on myself.

Most participants stated that this process of acceptance was the most important step on their path to improvement (P1, P2, P4–P9). Acceptance was described as a broad concept, including acceptance of symptoms and impairments, but also acknowledgement of the unexplained nature of symptoms and the interwoven relation between body and mind (P1, P2, P4–P9).

Quote (P4): I also think that it's a certain acceptance that some things in life are intangible. Just accept it. Like: hey, I've been too busy in my head and now my wrist hurts. I don't know how it's possible, but it is how it is.

**Adjustment of coping styles:** All participants described that they developed new and effective coping styles, mostly supported by therapists (P1, P2, P4–P8). Participants started pacing activities, making achievable plans, and creating balance between activity and rest. They also worked on the recognition and acceptance of their limitations.

Quote (P8): I like going out at night, but that's just not always possible. That's when I have to respect my limitations.

Some participants had become inactive to such an extent (P2, P5, P9), that a slow and gradual expansion of their daily activities was necessary.

Quote (P9): Well, I didn't know. To go home and sit down... was that a solution? The pain remained anyway. So I decided to break through it. Not too much, it's not that I went for a marathon or something, but I finished my walk.

All participants underlined the importance of relaxation. Participants described various effective relaxation exercises.

Quote (P2): It helps me to relax, especially in difficult times. I have an audiotape with sounds of walks in the forest and walks on the beach. Then I lay down on my bed for half an hour, just relaxing and listening. And when I am going through a difficult period I do it every day. When I feel good I don't do it at all.

Most participants decided to be more open about their symptoms towards family and friends (P1, P2–P4, P6, P8, P9).

Quote (P8): I've noticed that the more I open up to others, the more I get back in return... If you are open and if you show your vulnerability, people know what's going on and they can come up with things. They can give you advice...

Another important factor that many patients mentioned was a change in perception (P1, P2, P4, P5, P9). They used to focus on their impairments. After accepting symptoms, they started to focus on their achievements in spite of their symptoms.

Quote (P4): Now, when I start worrying, I can say to myself: stop worrying and be happy with the things that you have. And

be happy with the things that you've achieved today, instead of focusing on the things that didn't work out... That helps me.

**Treatments and therapists:** It was important to all participants that from the initial consultation on the GP took their problem seriously by being truly interested and empathic. After this process, participants expected their GP to refer them for further treatment (which happened in all cases).

Received therapies varied from therapies in primary care (i.e. physiotherapy or treatments by a psychologist) to multidisciplinary specialized MUPS programmes. Many participants had also received complementary therapies such as kinesiotherapy (P5), haptotherapy (P7) and natural medicine (P8). The therapists had to meet the same criteria as the GP. If they took the patient seriously, they were positively valued, irrespective of treatment outcomes.

Quote (P6): By the way, the rheumatologist of this hospital: she was a nice person. How she took the symptoms seriously, and how she took me seriously as a person. Even though she couldn't help me, it felt very good.

When a relation of trust was established, patients appreciated it if a therapist was being

honest, reflective and strict if necessary.

Quote (P7): She entered the dialogue in a different way and stimulated me to self-reflect. Like: "ok, but how will you accomplish that?" She really made me think deeper.

According to the participants, the ideal therapist should have a coaching role, is expected to be supportive and to provide coping tools. All participants described useful theoretical models provided by therapists, most of them based on a vicious circle.

Quote (P6): Well, you have muscle pains. Because of that you go slumping on your couch. Then you start feeling depressed. Then you get less active. And then you become tired. And finally, because you're so tired... At the end it comes full circle.

It was important to all participants that provided treatments fitted their personal life. Personalizing treatment contributed to compliance. Most therapists were open to this, but one participant was not allowed to personalize treatment (P9). As a result, she decided to stop therapy and to develop her own treatment, based on useful components of earlier therapies.

Quote (P9): From the start it was clear to me that sports formed the core of therapy. And I just missed the point of that. Cause if you don't like sports, if it is really bothersome to you... well, then sports won't help you recover.

Several complementary therapies were described as most effective, as therapists took time to build a relationship of trust and combined psychological components (e.g. talking session) with physical components (e.g. massage) (P5-P8).

Quote (P7): Sometimes, she was very harsh to me (in conversations), but afterwards she helped me relax during the last 15 minutes. I was invited to lie on the massage table and that made me quite... I just felt relaxed again when I left her.

Several participants missed this multidimensional approach in regular treatments (P1, P4, P8, P9).

Quote (P4): Dry needling seemed to have some effect. I tend to think that the physical aspects were treated by pricking the muscles. But, as things still weren't right in my head, symptoms recurred after a few months

Some participants had received professional group therapies (P1, P9), others talked with fellow-sufferers in private (P2, P4, P8). Both groups described support of fellow sufferers as useful, as contact with peers resulted in a higher level of acceptance and in exchange of effective coping strategies.

Quote (P1): You are together with people who understand you. I told them: "you don't want to know how I feel at night..." And then I saw six people nodding. That is delightful, and then you really start accepting your symptoms.

**Future expectations:** All participants were positive about the future, as they now had the tools to deal with emerging symptoms. However, they also emphasized that dealing with MUPS is a continuous process. One participant (P3) was suffering from a relapse at the time of the interview. Within a few weeks after completing the last questionnaire, symptoms had worsened due to negative life events. She was again struggling to accept symptoms.

This continuing influence of negative life events was underlined by all participants. Most participants experienced that development of symptoms can occur very quickly, while recovery takes a lot of time and patience. Therefore, they had to stay focused on their coping strategies, even in symptom free periods.

## Discussion

**Summary:** We performed nine interviews with patients with improved MUPS. It was remarkable that all invited participants were enthusiastic about participation. The interviews revealed a high level of similarity in the phases leading to symptom improvement: after experiencing a personal crisis, participants searched for help (mostly by visiting their GP), were more open to offered therapies than they were before and reached a higher level of acceptance of symptoms and consequences of these symptoms. This acceptance resulted in a strong motivation for change of coping styles. Participants took control of their own well-being, i.e. by pacing activities, acknowledging physical boundaries and relaxing effectively, mostly supported by therapists. This ultimately led to symptom improvement.

Our findings indicated that acceptance of symptoms and their consequences formed the key ingredient of coping with MUPS effectively. This finding leads us to the conclusion that without a certain level of acceptance further treatment steps may be ineffective. As a personal crisis forms the strongest motivator for acceptance, it may be impossible to externally force it. However, participants indicated that professional support on their way to acceptance was beneficial.

The vulnerability of the improved state of MUPS was underlined by the finding that the one participant suffering from a relapse was again struggling with acceptance. This experience was acknowledged by other participants: when you

feel good, it is easy to accept small physical impairments and to cope adequately. But when symptoms aggravate (usually due to stressors in personal life), it becomes much harder to accept them. In those situations, when adequate coping is most needed, there is a risk of falling back in ineffective coping patterns.

**Strengths and limitations:** We were surprised that data collection could be ended after 9 interviews. It seems that experiences of patients with improved symptoms are quite overlapping. This strengthens credibility of the findings.

All invited participants were willing to participate, indicating that non-response bias was not an issue. However, as all participants were already participating in the PROSPECTS study, we may have interviewed a 'positive' selection of patients with MUPS, willing to participate in scientific research. Most participants were female and lower educated, leading to a representative sample, as prevalence of MUPS is higher among these subgroups. However, potential additional insights of other groups may have been missed. A final limitation concerns the fact that patients were asked about their experiences retrospectively. Therefore, recall bias may have played a role.

**Comparison with existing literature:** To our knowledge, this is the first study to interview MUPS patients about factors contributing to improvement. We believe that interviewees provided useful information about the crucial role of acceptance. The positive effect of acceptance on illness behavior and symptom severity was also described in patients with rheumatoid arthritis [12-14] and in adolescents with Diabetes or Cystic Fibrosis [15]. This indicates that to a certain extent dealing with MUPS may be similar to dealing with some chronic diseases.

Reported coping strategies highly overlap with those in theoretical literature. This finding is not surprising, as most participants learned their new strategies from therapists. However, participants provided useful clues about which specific coping styles are most effective (e.g. pacing activities).

When it comes to treatments, several participants described complementary therapies as most effective. They appreciated that such therapies consisted of physical as well as psychological components (a multidimensional approach). However, available therapies in primary care are often one-dimensional (e.g. physiotherapy) [16]. According to participants, these treatments are less effective. This need for a broader approach in treatment was described before [17].

Several participants experienced benefit of support from fellow-sufferers. It was described before that peer advice may have a higher impact than advice of a therapist [17]. Participants of this study especially valued the exchange of coping strategies. Therefore, it may be useful to offer therapy to groups of patients with different stadia of MUPS, as more "experienced" patients could share their strategies with others. This has not yet been described in studies on group therapies.

### Practice and research implications

Our findings once again show that it is very important to take patients with MUPS seriously by being truly interested and empathic. It seems important to recognize different levels of acceptance and motivation for change, and to offer MUPS therapies at the right moment. Therefore, a good doctor-

patient relationship is essential. When a patient shows a certain level of acceptance, it can be useful to stimulate the intrinsic motivation for change by exploring and resolving ambivalence about behavioural adjustments, for example by motivational interviewing techniques [18].

Participants reported to benefit from various therapies. They experienced that a therapist is most effective when taking a coaching role, providing a theoretical framework for the symptoms and providing coping tools. Theoretical models containing vicious circles were most often described, suggesting that these models may be most useful. Participants reported a certain mismatch between their wish for multidimensional treatments and the one-dimensional treatments that were offered. A future challenge may be working towards a more multi-dimensional approach in MUPS treatments in regular health care.

As this study had a qualitative design, findings aimed to offer theoretical insight, not reproducibility. Consequently, findings of this study cannot be extrapolated to other subgroups of MUPS patients. Future research needs to address the experiences of patients who have not yet improved. In addition, it needs to be investigated if the identified phases and coping strategies are indeed associated with a more favourable course of MUPS. Acceptance of symptoms formed a key ingredient of coping with MUPS effectively. In future studies it may therefore be interesting to assess the effectiveness of treatments that focus on this acceptance, such as the relatively new 'acceptance and commitment therapy' (ACT), which uses acceptance and mindfulness strategies, as well as commitment and behaviour change strategies to increase psychological flexibility [19]. A final area of interest is the effectiveness of multidimensional treatments and group therapy.

### Conclusion

Acceptance of symptoms and their consequences seems to be the most important condition for coping with MUPS effectively. As a personal crisis often forms the essential motivator for this acceptance, it may be something that cannot be forced by therapists. Nevertheless, GPs and therapists can support patients on their way to acceptance by being truly interested and empathic. As a result, different levels of acceptance and motivation for change can be recognized and MUPS therapies can be offered at the right moment. When it comes to treatments, a wish for multidimensional therapies in regular health care was identified.

Once improved, maintenance of the improved state of MUPS forms a continuous process, as the balance is fragile and relapses may occur.

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**Competing interests:** None of the authors has competing interests to report.

#### Abbreviations

ACT acceptance and commitment therapy

GP general practitioner

MUPS medically unexplained physical symptoms

**Table 1:** General characteristics of participants.

Number	Gender	Age	Habitat	Educational level	PHQ score T0	PHQ decrease T1/2	Main symptoms:
1	F	29	City	Higher professional education	12	5	Tingling limbs, joint pain, and fatigue
2	F	55	City	Preparatory secondary vocational education	19	9	Burning sensation of tongue, pain in back and shoulders and anxiety symptoms
3	F	56	City	Preparatory secondary vocational education	14	8	Headaches, fatigue, sleeping problems and pulmonary symptoms
4	M	37	Rural	Senior general secondary school	18	8	Joint pain, concentration problems, tingling limbs and depressive symptoms
5	F	57	City	Junior Secondary Technical School	22	16	Dyspnoea, cough, palpitations and stomach pain
6	F	35	City	Preparatory secondary vocational education	15	5	Joint pain, pain in back and neck and fatigue
7	F	59	Rural	Junior Secondary Technical School	13	13	Chest pain, lump in throat, fatigue and depressive symptoms
8	F	55	City	Higher professional education	20	12	Bowel problems, joint pain, muscle pain and fatigue
9	F	46	City	Senior general secondary school	14	6	Sleeping problems and muscle pain

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