Persistent problems in the Dutch health care system: learning from novel practices for a transition in health care with the UPP framework

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Chapter 4: The clinic for unexplained diseases

Chapter three dealt with the first part of the iterative process of identifying and unravelling persistent problems in the Dutch health care system. It yielded features and mechanisms of this system. In this chapter, and in chapter five, the regime elements that may contribute to the reproduction of enduring problems are examined in light of what happens when the practices in focus (see chapter two) try to deal with identified problems. The specific aim of this chapter is to further unravel the mechanisms of reproduction. To do so, the problem definition and experiences of a novel clinic dealing with patients with medically unexplained diseases are analysed. This is done by following the rationale as presented in chapter two. When bringing the conceptual framework of systemic reproduction to the actor level, the focus is on a practice that is participating in the debates about enduring problems; a practice that implicitly or explicitly tries to deal with identified negative side effects of contested regime elements. The novel practice in focus does not have to have the explicit aim to contribute to a system innovation, but should be inclined to improve accessibility, acceptability, and quality of care. When attempting to do so, the new clinic may challenge systemically embedded notions, such as the systemically embedded mind-body dichotomy that features in this chapter.

The analysis presented in this chapter is the result of a triangulation of sources, and is presented as a series of answers to the guiding questions developed in chapter two (section 2.4). Where sub question a) was (tentatively) dealt with in chapter three, the content and structure of this chapter follows questions b) to e). The use of a combination of methods (triangulation) has the explicit aim of evaluating the knowledge acquired from different perspectives and, in doing so, reduces the risk of systemic biases or limitations of a specific method (Maxwell, 1996). Various data sources and methods were used (participant observations, formal and informal interviews, email conversations, literature research in (scientific) books and articles, newspapers, and the like), which complement each other. Before interviewing the initiators of the clinic, a short contextual review was done (section 4.1). After interviewing the initiators, other relevant actors were interviewed, like patients, again, the initiators, other health care professionals, and so on. Concurrently, sources in the literature and elsewhere suggested by the respondents were analysed. Besides data gathering, every interview had the aim to deliver a new lead, like relevant regulations that could be further investigated, a new actor to contact, or issues to research more in depth. As explained in section 2.2.3, the method developed has an iterative nature. This dictates an interactive model of research design, which implies that the essential elements of a study (context, objectives, research questions, methods, and validity checks) form an integrated whole, rather than being
linked to each other in a linear or cyclic sequence (Caron-Flinterman, 2005). The method and the reasoning behind it, as presented in chapter two, are thus further developed in the context of the practices analysed in this chapter and chapter five.

The interviews with initiators, patients, and other relevant actors were semi-structured, consisting of open-ended questions and relevant discussion points that were constructed in advance, which are meant to keep the interview focussed (Punch, 2005). This style of interviewing allows bringing up new and improvised questions, depending on the respondent’s answers (Varvasovszky & Brugha, 2000). At the same time, the interviewer is able to prevent the interviewee to elaborate too extensively. This means that in-depth information can be retrieved, with the respondent actively involved. Interviews took place at the respondent’s workplace or home and lasted for approximately 60 minutes. During the interview, only the respondent and myself (the interviewer) were present. All interviews were audio-recorded with consent of the interviewee. It was stressed that respondents remained anonymous. The interviews were transcribed and relevant quotes were time-coded by making use of the qualitative research analysis software Atlas.ti.28

The four layers of the interpretive frames (see section 2.2.3.2 and: Grin & Van de Graaf, 1996; Grin et al., 1997) were constructed during and after the interview in the context of relevant issues that were brought up in the literature and in earlier interviews.

Section 4.1 starts with a contextual review of the issues around patients with medically unexplained diseases. The information in sections 4.2 and 4.3 is based on three interviews with the two professionals — a professor in neurology and a psychologist — who initiated the clinic for unexplained diseases in an academic hospital in the Netherlands, and is supplemented with observations of patient visits and other sources.29 As this part of the method is actor-guided, the first two subsections describe the reasoning of the practice itself. Where these interviews are the starting point for the conduct analysis, the next part of reconstructing a system through the eyes of an agent is the context analysis. Building on identified issues relevant for the functioning of the practice, the focus is on what kind of support or impediment the practice experiences and what the underlying reasons are. The description in section 4.4 is based on ten interviews with patients, eight formal interviews with care professionals, a group discussion with patients and professionals,

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28 The interviews were transcribed by listening and writing down the story that was told while linking the sentences to time-codes. This means that the interviews were not transcribed verbatim, but meant to distil issues while keeping the connection to the original audio. If a section was coded as relevant for a certain issue the linked audio clip would be available for play-back for later reference and analysis.

29 The third interview, on August 7th 2008, functioned as a presentation of my findings and to allow the professor to respond to my depiction of his argumentation. On June 5th 2008 I did the same with a PhD candidate working with the clinic on a study to validate the intervention of the clinic.
participant observations, email and Skype conversations with a variety of actors, and the literature. When saturation (Marshall, 1996) regarding information relevant for the functioning of the practice and how it is supported or impeded was reached, the link between described success factors with negative side effects (historically informed system analysis), how the practice tries to overcome this (conduct analysis), and how the practice is supported or impeded (context analysis) was constructed in section 4.5.

4.1 MUPS and a new clinic for unexplained diseases

It is estimated that roughly half a million people in the Netherlands suffer from physical pains and impairments for which medical doctors have no explanation.30 For patients with these ‘vague complaints’, a diagnosis is often difficult to make, because no underlying pathology can be identified. After a long diagnostic process, during which the physical complaints are increasingly affecting the overall quality of life of the patient, the illness might then be classified as, for instance, ‘chronic fatigue syndrome’ or ‘fibromyalgia’ 31 — diseases that are themselves contested. And so it has happened that a patient was congratulated on being perfectly healthy, since no physiological abnormalities showed up on scans, while being wheelchair-bound because of enduring pain. 32 One of the more commonly used classifications for these ‘vague complaints’ is Medically Unexplained Physical Symptoms (MUPS).

People suffering from MUPS are not an anomaly; an estimated 2.5 per cent of all patients going to a general practitioner (GP) fall under this category (Verhaak et al., 2006), and specialists in (academic) hospitals are often confronted with this group of patients (Dirkzwager & Verhaak, 2007). When adequately dealing with the symptoms fails, MUPS can become chronic, causing both a burden for the patient and a burden to health care providers. Furthermore, MUPS are a burden to society at large because of high costs due to sick leave and extensive health care service use (Reid et al., 2002).

In reaction to this, a clinic for unexplained diseases (kliniek voor onbegrepen ziektes) was started in 2005 in order to alleviate the problems experienced by both patients and practitioners. This new clinic for patients with MUPS, also referred to as ‘the clinic for vague complaints’, aims at providing integrated, multidisciplinary care in which medical doctors try to overcome the dichotomy between body and mind. According to the founders of the clinic, symptoms in these patients can neither be fully explained by

30 Vermeulen, M., ’VU opent kliniek voor vage klachten’, de Volkskrant, 09-01-2008, Amsterdam: PCM Uitgevers BV.
31 According to the American College of Rheumatology (Wolfe et al., 1990) fibromyalgia is characterised by widespread musculoskeletal pain of at least three months’ duration, fatigue, poor sleep and tenderness on palpation in at least 11 of 18 specific tender points.
32 Vermeulen, M., ‘Kerngezond, maar wel in een rolstoel’, de Volkskrant, 10-01-2008, Amsterdam: PCM Uitgevers BV.
physical factors nor by psychological factors. Because conventional, specialised health care does not acknowledge the possibility that psychological and physiological factors act synergistically, patients end up being sent to a variety of specialists without ever getting a definitive diagnosis. Eventually, the complaints are interpreted as non-physical, and patients are referred to a psychiatrist. However, because patients do not usually accept a psychological explanation for their physical symptoms, they feel they are not taken seriously. Besides professionals, politicians, like Hans Hoogervorst (the former Dutch minister of Health, Welfare, and Sport), who say patients with MUPS are ‘just complaining about nothing’, increase this feeling of disregard among these patients.

On January 9th 2008, de Volkskrant reported on the opening of another new clinic aimed at treating people with MUPS. This clinic is a cooperation between an existing clinic for mental health care and the VU University medical centre (VUmc) in Amsterdam. In reaction to the article on the new clinic, a patient sent in a letter to de Volkskrant, arguing that rather than his complaints, the diagnosis is vague. Frustrated, he added that he is not the one who is falling short, but medical science is! The question then is: are half a million people just complaining? Is it the patient, or is it medical science that is falling short? Even if the patients are, as some argue, imagining their complaints, the total number of patients, as well as the amount of medical procedures that lead to no diagnosis or cure, is still causing a huge financial burden on society. It seems that the health care system is unable to sufficiently help or deal with these patients in order to structurally relieve this burden. Is this because of the conventional care paradigm of medical science as the founders of the new clinic suggest? As part of the application of the method developed in chapter two, the clinic for unexplained diseases was followed and analysed.

4.2 The practice; solutions for what care-problem

In 2005, a psychologist and a professor in neurology — who had met each other in the academic hospital where they both worked at the time — felt a new approach was needed to deal with a remarkable group of patients. The

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34 ‘Brief van de dag; Kliniek voor vague klachten’, de Volkskrant, p. 11, 10-01-2008, Amsterdam: PCM Uitgevers BV.
35 The analysis in this section and the next section departs from three interviews with the initiators of the clinic for unexplained diseases. The first interview took place on August 21st 2007 in the office of the neurologist in the academic hospital. I was under the impression that I was allowed to participate in a multidisciplinary team meeting, just to get an idea about how they operated, and to make a next appointment. But as it turned out it was an interview with both the initiators for 45 minutes. After many months of contextual research and interviews with patients, the second interview took place on May 6th 2008 with the psychologist in her private practice (not part of the...
professor and practicing neurologist had noticed that about one-third of the patients who visited the regular neurological outpatient clinic appeared to have persistent pains and functional impairments that suggested a neurological basis, but for which no physical evidence could be found. These patients usually had consulted many different health care professionals over a time span of more than a year. The point of departure for the psychologist was the question why some people with, for instance, advanced stages of cancer went to work, while other people with relatively minor physical complaints gradually fell out of their daily — and eventually work — routine when no immediate cure was found. It seems some patients with undiagnosed, not openly life-threatening complaints can turn into chronically ill patients while going through the health care system. In these cases, the underlying cause of the illness was uncertain, and doctors as well as patients became extremely frustrated. Consequently, the initiators felt a new approach for dealing with these patients with ‘vague complaints’ was needed in order to prevent that such patients would ‘disappear’ in the health care system without receiving appropriate treatment. The two professionals started the clinic alongside their regular work schedules. The secretary of the outpatient clinic, for instance, kept a separate calendar for appointments of these patients with the professor.36

In the first interview, the founders of the clinic explained that they had devised a short intervention to counter the problems of frustrated doctors and increasingly impaired patients. The aim of this intervention is, first of all, to stop the diagnostic route: no more referrals, no further medical examinations. As elaborated on in 4.3, this diagnostic route is part of the problem. If the neurologist somehow suspected an underlying pathology, appointments can be arranged with other specialists in the hospital, but the neurologist continues to be the main practitioner. There would be no referrals. When no underlying pathology is suspected, a basis of trust is established, and the patient is reassured that there is no hidden disease. When trust has been established,37 the patient is coached on learning to deal with the pain, and subsequently on reactivating himself.38 The initiators stressed that two or three sessions usually suffice. The first consultation is meant for an extensive anamnesis. Where a regular appointment takes 15 minutes, this one could take up to an hour.39 It is first made clear that the experienced physical pains and problems are real and not imaginary, even though no physiological

academic hospital) where she treats patients suffering from a burn-out. The third interview was with the neurologist in his office on August 7th 2008, where we discussed my findings.

36 This is something I noticed when accompanying a patient to her first consultation.
37 Without trust, no healing process is possible, according to the psychologist.
38 Or ‘herself’.
39 I participated in such a consultation on 23-4-2008.
evidence is visible. As patients tend to feel as if they lost control, the immediate goal is to reinstate the patient as the person in control. This point was stressed several times in the three interviews, and the importance was confirmed by other sources. During the anamnesis, the patient history is written down. The focus lies on events regarding the onset and development of the experienced disease, on what other doctors have reported, and on what the patient can say about how he or she was able to become more active in the past. When this story is written down, the neurologist explains his model of the neurological system in distress (see section 4.3) to reassure the patient. The main goal is to explain that further searching for a physiological cause, in the sense of an infection, a parasite, or a tumour, and so forth, is of no use because it is likely the complaints have another origin — an origin that has disappeared by now and will not be detectable anymore. But, just because no physiological cause can be found, does not mean the complaints are psychological. After that, the goal of the consultation and subsequent appointments is to tap into the self-healing properties of the patients. The focus lies on how the patient can do sports, or exercises, or resume work as soon as possible. The initiators emphasised that when the patient has made the switch that focussing on reactivation might be more productive than to stay focussed on the symptoms, treatment is already well underway. The treatment thus contains five important elements: recognition of complaints; reassurance; the notion that improvement is possible; but not without personal effort of the patient; and coaching. The idea is that if this approach is picked up by regular care practices, the treatment should commence as early as possible. Preferably these patients should stay out of the hospital. To make this happen, general practitioners should be educated to deal with these patients. To be able to connect to the regular care structures and referral systems, the founders of the clinic want to design a randomised controlled trial to validate their treatment evidence-based.

40 A PhD student working in the practice explained this in an interview (05-06-2008) as overcoming the problem of a negative diagnosis: when people present somatic symptoms without clear underlying cause, practitioners might say they ‘have to learn to live with it’, or just that their ‘pain is imaginary’.
41 Brandt, E., ‘Lichamelijk onverklaarbare klachten poli’, Trouw, 19-7-2005, Amsterdam: PCM Uitgevers BV.
43 To me, it seemed patients usually focussed on what happened and what symptoms they experienced, while being less interested in what the focus of the neurologist was, like, what actions in the patient’s life appeared to have a positive effect, such as taking long walks, or doing sports.
44 Although the clinic does not label it like that, the approach resembles a short form of cognitive behavioural therapy.
45 Based on observations of consultations.
4.3 The practice; premise and expectations

The section above is an answer to the guiding question of how the MUPS clinic as a novel care practice in focus organises itself (what solutions fit what (care)-problem). This section builds on that and structures information from the third layer of the interpretive frames of the initiators of the practice to answer the question of what the premise and expectations underlying the practice are, as well as what their insights are in terms of how the current (health care) system functions. The above described multi-layered care solution for a multifactor care problem is based on two intertwined lines of reasoning — as explicated by the initiators of the practice in three interviews and substantiated by the literature. One line of reasoning concerns the organisation of the current health care system, and one is built on neurobiological knowledge — again, as made relevant by the initiators.

When I asked the initiators why their intervention was suitable for patients with MUPS, they stressed that endless referrals, to the extent that it can be said these patients are ‘disappearing’ in the health care system, are actually underlying the condition of the patients. This process leads directly to frustrated professionals, rejected and chronically ill patients, and high health care service costs. According to the initiators, what appears to happen along this route is that patients come to a general practitioner (GP) with difficult-to-diagnose physical complaints. A GP, as a start, frequently orders a blood test when confronted with a patient presenting complaints that are difficult to explain. A GP typically tends to focus on physical complaints, ignoring other signals, like the patient telling about lying awake at night (an example I also found in Kappen & Van Dulmen, 2008). The risk of false positive test results, however, is said to be relatively high. This may result in further testing, leading to unfavourable effects, such as patient anxiety, high costs, and somatisation. A policy of watchful waiting is expected to lower both the number of patients to be tested and the risk of false-positive test results, without missing serious pathology.

However, many general practitioners experience barriers when trying to postpone blood testing by watchful waiting (also brought forward by: Van Bokhoven et al., 2006). When further tests give no conclusive answer, the patient is referred to a specialist, even though the GP expects that the specialist will not find anything either. According to the initiators of the new clinic, there are two main reasons for this. First, although the GP cannot discern clear diagnostic signals, he or she does not want to risk overlooking a serious illness — which would logically diminish the confidence of the patient in the GP (see also: Kappen & Van Dulmen, 2008; Van Bokhoven et al., 2009). Second, the patient may pressure the GP for further testing. This is based, first, on fear that some serious illness stays undetected and, second, on the idea that a physical explanation for the pain must exist, and therefore that a medical-physical, instead of a psychological, reason should be found.
Referral as such is, of course, one of the important tasks of a GP. The result of this, however, might be that the patient is not cured along the route that follows, but becomes chronically ill. Since the specialist does not find tangible evidence for physical abnormalities, as described in medical literature, he or she refers the patient back to the GP or to another specialist. As a result, the patient, after many inconclusive diagnostic tests, feels something serious must be wrong and becomes even more stressed and anxious. At some point along this route, the patient may then be referred to a psychologist; a referral usually refused by the patient because that would imply that ‘it is all between the ears’, while he or she experiences physical pain. In addition, even when the patient visits a psychologist, he or she might be referred back to the GP or another specialist, because the psychologist feels insecure about treating patients with physical pain, which might point to life-threatening illness. All this accumulates in an uncured, stressed, rejected, and chronically ill patient, as well as a series of annoyed medical practitioners who feel either helpless or inclined to reject whiny patients. Furthermore, societal costs are high, due to the use of diagnostic equipment, consulted doctors, and loss of labour-capacity of the patient.

According to the people who initiated the clinic for unexplained diseases, the way the Dutch health care system treats these patients interacts with an important neurobiological mechanism: long-term potentiation (see for a basic explanation for instance the textbook by: Purves, 1997). This means that when two neurons interact (via their synapses), their connection is strengthened. As a result, the more a neuronal pathway, covering numerous neurons and synapses, is used, the easier it is used. In patients with MUPS, there often is an organic trigger, like a relatively severe fever. That is the start, and usually most people get over it, albeit after some weeks or months. Others, however, can become trapped in vicious circles of monitoring their symptoms and pains. Combined with the stress about what they feel, they become hypersensitive to their symptoms, which is why these actually increase, in the end restricting their activities, leading to frustration and demoralisation. This, in turn, causes more symptoms, more concerns, and more physical changes, so much so that what started it all off is no longer what is keeping it going. The trigger of this (neurological) distress is no longer even detectable. As long as the patient stays focussed on the physical impairments, they will not go away. Desensitisation is needed.

To desensitise the patient, it is necessary to reactivate the patient: doing sports, exercising, or resuming work as soon as possible. The patient should not be afraid to overstrain something, but coaching on gradually

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46 This statement of the initiators was confirmed, without being asked, by all ten patients followed and/or interviewed, who kept on stressing the physical nature of their pain.
47 Think of a highway: an increase in traffic on a certain road leads to the building of a broader road, which in turn attracts more traffic.
48 Usually referred to by professionals as ‘symptom awareness’.
building up is necessary. Although the illness is not the fault of the patient, he or she has a vital role and responsibility in combating it, because physiology and behaviour interact and are even inseparable. The health care system is, however, ill-equipped to organise adequate care, because it is organised based on a specialised division between these two.

4.4 The practice; support and impediment

The sections above comprise the conduct analysis of the novel practice in focus, containing the problem definition, supplemented with observations of patient visits and other sources. This problem definition contains the solution to the problem as formulated by the initiators (layers one and two of the interpretive frames), and the reasoning behind why the introduced solution is appropriate (layer three). From this analysis, a number of issues emerged as well as relevant actors in the direct environment. These issues and actors are the starting point for the context analysis, focusing on the system surrounding the practice and the support and impediment the practice encounters. This analysis is based on ten interviews with patients, eight formal interviews with care professionals, a group discussion with patients and professionals, participant observations, email and Skype conversations with a variety of actors, and the literature.

4.4.1 Institutional setting

It appears the new clinic for unexplained diseases can first and foremost exist because of the academic and contractual position of the head of the neurological department. Because he is the head of the department and a professor in neurology with a teaching obligation at the academic hospital, he has more freedom to schedule his own time. This creates room — albeit at his own ‘expenses’ — for appointments lasting up to an hour instead of the regular ten to fifteen minutes. However, the consultations with these patients have to remain outside the regular electronic hospital agenda. When becoming part of the administrative system, the hours spent would have to be justified to both the hospital management and insurance companies. Both require medically validated treatments, as elaborated on in section 4.4.4, but other reasons also play a role.

To begin with, the professor said the management was unwilling to fund the new treatments, partly because other specialists, competing for limited funds, had lobbied against this program. Further research on this issue turned out to be difficult. The idea that in academic hospitals several partnerships of specialists compete for scarce funding is not new (Lieverdink, 2001). However, interviewing relevant specialists to learn more about underlying reasons besides financial ones was problematic, and I found no other professionals willing to talk about the new MUPS clinic in an interview.
setting. They usually claimed not to have the time. One specialist explicitly said this clinic ‘did not exist in this hospital’.\textsuperscript{49} Another specialist stated that ‘such care is not the core business of the academic hospital’, referring to mental health care, and that he had an appointment and had to go.\textsuperscript{50}

Because of the lack of interest among the hospital’s specialists to discuss the issues the clinic is dealing with, it might seem these were not considered of importance for the daily professional job routine. However, between 2007 and 2010, I regularly discussed my research with young medical professionals within my social network,\textsuperscript{51} and they all expressed great interest because they encountered ‘these kind of patients’ on an almost daily basis and felt inadequate to deal with them in a satisfactory way.\textsuperscript{52} The underlying dichotomy between body and mind always surfaced, and most of the discussion was about: 1) whether these patients even should be treated in a hospital — in contrast to an institution specialised in mental care; 2) after I explained that these patients are a fact and that referring will not make them go away, how to diagnose those patients if no pathology can be found; leading to 3) that they cannot do anything without a diagnosis. Further conversation usually was about definition-issues. One neurologist,\textsuperscript{53} classifying herself as ‘young assistant’, was intrigued by the subject but stayed confused as to when one would consider a patient a patient with MUPS — and thus whether she would be able to provide a treatment. She later asked whether conversion\textsuperscript{54} is part of MUPS, or if that is ‘just psychiatry’. And she wondered why complaints about depression are part of the issue and not ‘just a depression’, as something unrelated. Based on these and other conversations, it appears that: 1) patients with ‘vague’ complaints are a common problem in hospitals; but 2) are largely seen as people who should not be accepted in a ‘professional medical institution’, but treated elsewhere.

According to the initiators, another somewhat counterintuitive reason for the hospital management to withhold funding was the expectation that a horde of patients would flood the new practice. This was known to have happened before to a practice in Nijmegen\textsuperscript{55} that deals mostly with patients

\begin{footnotesize}
\begin{itemize}
  \item \textsuperscript{49} Telephone call February 2008. When I said it did, she said she had not heard about it, so had nothing to say about it. Not in an angry voice or such, she just stated a fact.
  \item \textsuperscript{50} Telephone call February 2008.
  \item \textsuperscript{51} Admittedly, mostly at parties.
  \item \textsuperscript{52} The husband of a friend of mine explained, for instance, that he was thinking about leaving internal medicine (\textit{interne geneeskunde}; the general, not specialised, department of hospital care) because he too often got the feeling that there was too little he could actually \textit{do}. Especially those ‘annoying patients without a univocal solvable problem’ were a cause of discomfort to him. According to him, his department was not enough like surgery — cut out the problem and you are done. His department involved too much pointless messing around.
  \item \textsuperscript{53} We met at a social occasion on November 30\textsuperscript{th} 2007 and had a subsequent email conversation. The remark on classification is from December 12\textsuperscript{th}.
  \item \textsuperscript{54} The process by which difficulties in the patient’s life lead to physical complaints.
  \item \textsuperscript{55} Also known as ‘Nijmeegs Kenniscentrum Chronische Vermoeidheid’: \url{http://www.umcn.nl/zorg/afdelingen/nkcv/Pages/default.aspx}
\end{itemize}
\end{footnotesize}
suffering from chronic fatigue syndrome (CFS, also commonly known as myalgic encephalomyelitis (ME)) \(^{56}\) and the prospect scared off the management and staff of the hospital.

Other relevant institutional actors for the clinic are insurance companies. Surprisingly, although great cost reduction can be expected because less expensive medical tests are needed, no insurer has so far agreed to sponsor the project. During the first two years of the project, and on several occasions, insurance companies’ employees had been convinced to support the project. However, every time the support seemed to be secured, the people involved were transferred or the company involved got caught up in mergers, and nothing was made official. Since the new treatment comes with a story, and without solid scientific evidence that can be easily presented, it is difficult convincing people over and over again.

In general, the academic surroundings appear not to be hospitable to medical treatments that do not have a clear and demarcated diagnosis-treatment route. The professor in neurology once turned to me and said, almost in a fatherly manner, that he would never ask a young professional to do research in this field, because it ‘would be a terrible start of a career’.\(^{57}\) He claimed that the kinds of ideas on which his practice is built, not only have a low medical status, but will inevitably lead to severe clashes with the dominant medical discourse.

For patients with MUPS, the endless referrals can be seen as both a problem in itself and as one of the causes of their chronic illness. From the first medical encounter onwards, a multidisciplinary approach might help: an organisation that creates an arrangement of care providers around a patient, instead of a process in which a patient visits separate specialised care providers. The new clinic tries to circumvent this problem of compartmentalised care in which the patient as a whole is dissected in analytical blocks, blurring the greater picture. Yet, the clinic has no direct means to do so. First, the initiators tried to arrange a team of specialists for interdisciplinary meetings to discuss the patients’ problems, but the separate departments were unwilling to contribute or just did not have any affinity with the subject. The second solution of the professor was to organise a personal patient record himself, sending patients to other specialists if deemed necessary, while remaining the central contact person. One could say he took over the role of the general practitioner, because the general practitioner is too far away from the specialists, both in distance and in network, to keep adequate control over the process and the patient in that process. He thus

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\(^{56}\) From a casual talk in 2010 with a former employee of the new clinic at the VUmc (mentioned in section 4.1) I learned that in the first year of the new clinic they had a problem with too many patients and lack of staff.

\(^{57}\) A couple of months later he had appointed a PhD student. This PhD student told me, on October 9\(^{th}\) 2008, that the professor had warned him as well. When the PhD student applied for the position, the professor said that this might become his ‘Waterloo in neurology’, and that he should sleep on it and call back tomorrow.
organised multidisciplinary care first and foremost with the psychologist with which he started the clinic, and secondly, through him as organiser and integrator of separate diagnoses.

This also gives him the opportunity to make some sort of deal with patients. Patients are, at first, looking for a physical diagnosis. The professor both does not want to miss a serious disease and needs to convince the patient that there is no hidden disease. The central role he created for himself gives him the opportunity to send patients to specialists he knows personally, who can do a regular consultation — which is thus covered by regular reimbursement policies — without the unwanted effect of unsatisfied patients and frustrated professionals. He can explain to both parties beforehand what can be expected from the consultation and can discuss the results with the patient afterwards. This enables him to integrate the separate diagnostic pieces into one general anamnesis.

4.4.2 Value of diagnosis

An important issue in the reasoning of the novel practice is the diagnostic track that patients follow while being bounced around through the health care system. When patients meet with the initiators of the practice, the question of what is wrong with them, which relates to the question of what the medical diagnosis of their condition is, is the first problem that has to be tackled. From the start, the patient has also been very focussed on obtaining a diagnosis. The quest for a diagnosis, however, is what is turning these patients with minor complaints into chronically ill patients.

It appears that both health care professionals and patients need a diagnosis, and that this need is blocking actual treatment. A health care professional needs a diagnosis to act because the health care system supposes, both in rationale and in organisation, a clear diagnosis to prescribe further action. The result of every consultation needs to be a diagnosis or a referral to get one. For instance, while following a patient, I witnessed a cardiologist conclude that a patient had ‘non-heart-related chest pain’. This really means the cardiologist was not able to successfully diagnose a cause for the patient’s chest pain, but the way he phrased his uncertainty increased the patient’s fear. The quest for a diagnosis can thus lead to fear and endless referrals. In this process, a patient becomes objectified more and more as a physical body with an abnormality.

A patient then needs a diagnosis to regain a feeling of control. As long as there is no diagnosis, there always remains the possibility of a deadly disease. Furthermore, patients appear to look for objective confirmation of the legitimacy of their complaints. All the patients I interviewed or followed expressed more or less explicitly that they needed to know that they had a real disease. They needed to know that what they experienced was not imaginary, and — directly linked to the existence of a real disease — not their
fault. Furthermore, they needed a diagnosis to show their friends, family, work, social security, and so forth. One patient I followed finally got a diagnosis after one and a half year: fibromyalgia. The rheumatologist gave her a leaflet with some background information. This made her very happy because she could at last explain and show to family and friends what was going on. This disease is however not officially recognised, which meant her unemployment benefit — earlier granted because of her illness — was revoked.

There thus is the need for a diagnosis and as such a classification. When a diagnosis is found, a patient fits in the system, both institutionally and culturally. (On the other hand, it could also mean that a diagnosis puts you outside the system, as in the case of the fibromyalgia patient who lost her unemployment benefit.) To come to this classification, the patient also objectifies himself, thereby excluding other causes of action than searching for a diagnosis, in order to get medical treatment. In the case of MUPS, it seems that patients try to, or really need to, externalise the cause. But because they do, they also externalise the solution, whereas in the case of MUPS the participation of patients in the care trajectory is quintessential.

4.4.3 Parable of a MUPS patient

The practice in focus points at the problem of patients being bounced around through the health care system. Furthermore, the experiences as well as general stance of patients appear to be important factors, the second remaining somewhat of a mystery for the initiators. Because the initiators made clear that the problem extends beyond the patients that come to the neurology department of the professor, I widened the scope of my search to patients and professionals outside the realm of the new clinic for unexplained diseases. Based on the stories of patients obtained through interviews and casual talks, a parable of a MUPS patient is constructed. This parable is not an individual story of one patient. Also, it is not a statistical meta-analysis. This story is the result of an iteration between a set of patient stories, the problem definition of the novel practice, and the literature. The endless referral of patients and the resulting effects was the recurrent theme in all interviews with the initiators. The fact that patients see a whole series of professionals

58 Interview October 3rd 2008. She worked at the time for a bureau that helps students with a physical handicap to make their studies possible. During the interview she repeated a couple of times how she could relate to those students, and sometimes she gave me the feeling that she used to be kind of jealous, for these students had something to show that justified their problems with studying.

59 Or ‘herself’, obviously.

60 Although it takes the story of one patient I had most contact with as point of departure.
was acknowledged by all the patients interviewed.\textsuperscript{61} However, where the initiators of the practice stressed the role of the health care professionals, the patients’ life stories remained unclear, whereas this might shed light on why the outcome of a single regular consultation is a referral without cure. This parable is meant to give insight into the experiences of the patients themselves, within as well as outside the realm of the health care system.

On April 15\textsuperscript{th} 2008 I received an email from a woman, let me call her Els, whom I had met the night before at a seminar of the professor of neurology in ‘De Rode Hoed’ in Amsterdam about patients with MUPS.\textsuperscript{62} Els stated that, after a year of ‘hassling with doctors’ (dokteren), she was delighted to have finally heard a story of a doctor who was ‘genuinely concerned’ about her group of patients. We had talked about her experiences of the past year, and she said she was thrilled to finally share her experiences with someone who was interested in exploring underlying causes. She explained that a year ago she suddenly became extremely tired; everything was too much. She had been unable to walk for three months. If she tried to walk, she would just collapse after a couple of minutes. She became hypersensitive to inputs of all sorts, like sounds, lights, and a series of other stimuli. When talking to someone she felt like every word smacked her in the face. Doctors had no idea what to do. Els had the feeling they just did not believe her.\textsuperscript{63}

Over a period of one and a half years, she visited a wide range of practitioners, both ‘regular’ (meaning western medicine) and complementary health care practitioners. The first months were spent visiting her general practitioner. He had ‘not been keen to discuss the problems’ of Els. He would say things like ‘well, everyone has something every now and then’,\textsuperscript{64} and that it was probably nothing. For Els, symptoms got worse over time, so she would visit her GP again and again. Most of the time she would burst into tears, which actually seems to stimulate the GP to talk the symptoms down.\textsuperscript{65} He would sigh and would tell her to go see a psychologist or send her to physiotherapy, again. So they tried and tried and tried. Els had the feeling there was more, so she wanted a ‘real’ referral, a referral to a specialist. But he stayed away from that.\textsuperscript{66}

When Els visited a psychologist he noticed that, during their conversation about stress and her mental wellbeing, she constantly had a hand at her abdomen. He asked why that was; did she feel pain there? When she confirmed that she did, he replied that that was not his field of expertise.

\textsuperscript{61} As well as on Internet forums, in newspaper articles, etcetera. It is the basic complaint of this group of patients.
\textsuperscript{62} April 14\textsuperscript{th} 2008, Wetenschapscafe café vage klachten, De Rode Hoed, Amsterdam.
\textsuperscript{63} Conversation April 14\textsuperscript{th} 2008 and email of April 15\textsuperscript{th}.
\textsuperscript{64} Dutch original: \textit{ja, iedereen heeft wel eens wat.}
\textsuperscript{65} One day she was more relaxed and self-confident and told the practitioner that she wanted to see a rheumatologist, and he said: ‘okay’.
\textsuperscript{66} Interview October 3\textsuperscript{rd} 2008.
and that she should discuss that with a GP. 67 Because Els herself has a practice as a holistic healer, I asked what she would do if a patient like herself would come to her practice. She said that she would send him or her to the doctor, because it was physical. She made clear she can only ‘help people cope’, not really look into what is wrong. 68

Els went to see, on her own account, an orthopaedic manual physical therapist. He said he could massage the vagus nerve, which she had come to see as being connected to collapsing while walking. Upon entering the man told her to lie down and said that he was ‘just a mechanic’ and that he would fix her. Els told me she felt as if she was a car that needed servicing. Sadly, the treatment did not help. 69

During this period, Els began looking for answers the practitioners were unable to give her. She searched the Internet and discussed her symptoms on Internet forums almost every day. 70 Friends and family also participated in the search and regularly suggested underlying causes, treatment options, or advised her to go to a particular professional, whether from regular or complementary medicine, about whom they had heard good stories. 71 Interestingly, every now and then she had good periods, days in which she was sick of thinking about causes and possibilities and just went out to dance. She could feel positive and energetic. But since she was still on sickness benefit, doctors as well as friends and family kept looking for causes and treatments. There were constant ‘voices’ asking whether she had tried this or that. They were helpful and genuinely concerned people that meant well, but also kept on bringing up new possibilities to try even though previous treatments had been unhelpful and stressful in itself. But friends and family were persistent: ‘there is no harm in trying’. So, she would go to a practitioner, again, to present a new hypothesis. 72 These hypotheses professionals usually dismissed instantly.

Then one day, after one and a half year, a rheumatologist asked her what she herself thought was wrong. He then basically agreed with her and without giving her a treatment option, he just stated that the disease would not kill her, that she would be able to reach a ripe old age, handed her a

67 Casual talk April 14th 2008.
68 May 9th 2008 during a walk through the park. This patient had insisted earlier that I should accompany her during a walk, because this is when she would suddenly collapse. Her complaint was that doctors never had the time to ‘be there when it happened’, and that when she was at the doctor’s office, nothing showed up.
69 Casual talk May 5th 2008.
71 Email from a friend of a patient on June 8th 2007, saying that his wife had suggested salmonella or legionella, ‘but that cannot be’, because salmonella implies vomiting and diarrhoea that should pass within a week, and legionella means a high fever. ‘Maybe Lyme disease?’
72 Interview with patient on January 28th 2009.
leaflet, and sent her away. She was tremendously relieved. Finally! A diagnosis! It meant the end of the endless searching and all the stress. At last she had something tangible to show to friends and family. Only later she realised this man had actually done nothing.

4.4.4 Trial to validate new practice

As introduced above, the management of the hospital, other specialists, and insurance companies considered it important that the new intervention developed at the MUPS clinic was validated in a medical-scientific way. Besides this pressure from the outside, the initiators themselves also thought it necessary to somehow measure the effect of the new treatment. As a result, a PhD student was appointed in 2008 to set up a trial and start patient-inclusion. To make this possible, a pilot study was started to investigate what kind of outcome measure is most suitable. According to the PhD student, this was already problematic. When measuring the effectiveness of a treatment, an outcome measure that measures in the domain of the intervention, for instance physical impairments, is needed. This is difficult in the case of physical complaints of unknown pathogenesis and where the group is very heterogeneous, while being treated by an intervention that is not fully defined and demarcated.

A few months later, the student had worked on setting up validated questionnaires to measure the outcome of the intervention of the novel clinic. The point of departure was a set of "Activities of Daily Living", questionnaires used in different fields to measure what people can or cannot do in daily life. Questions on the list ask, for instance, whether a patient is able to ride a bike for two hours or climb stairs. Validation of the devised lists, however, turned out to be extremely difficult. According to the PhD student, the problem is that if you ask whether one can climb stairs, you do not ask how difficult it is. The test thus ignores nuance and context. Patients with MUPS are usually still able to do everything; but they experience pain and fatigue, hence a low quality of life in general. The sensitivity of the scales is too low.

However, if one wants to improve the sensitivity, the symptoms and intervention in those symptoms need to be better specified as well. One must be able to prove that the chosen intervention is reducing the monitored symptoms, and not something else. In general, more generic questionnaires are very usable, but do not differentiate between different influences on the symptoms, like different diseases or social factors like sports or diet (Flokstra-de Blok, 2009). Generic questionnaires are thus useful to measure general

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73 Interview with a fibromyalgia patient, October 10th 2008.
74 Interview with PhD student, June 5th 2008.
75 Algemene dagelijkse levensverrichtingen. See http://nl.wikipedia.org/wiki/Algemene_dagelijkse_levensverrichtingen for a basic overview.
76 Interview with PhD student, October 9th 2008.
aspects of quality of life in order to determine whether a patient needs more home-care or a place in a nursing home or such. Yet, these lists are not evidence-based validated to measure the outcome of an intervention. For this, a disease-specific questionnaire is needed that is more sensitive, which increases the chance that clinically relevant changes as a result of the treatment can be measured (Flokstra-de Blok, 2009). Since patients with MUPS have no demarcated disease, no outcome measure can be statistically validated.

The logic followed here is the logic of the regular way of doing medical research, in which a homogenous group of patients in a double blind study is subjected to either the intervention or a placebo. Double blind means that both the professional and the patients do not know in which group the patient is placed. Because the professor of neurology basically has long talks with patients about their complaints and ideas about what might be wrong, upon which both decide together what will be the course of action, none of the conditions of a double blind study can be met.

4.5 Systemic reproduction of problems

The new clinic for unexplained diseases has a very interesting new approach to deal with a group of patients that experiences suboptimal care. While not formally proven, the new intervention appears to be very successful in actually helping patients who initially had relatively minor complaints and have become chronically ill while being bounced around the health care system. However, this new intervention is not a straightforward success story. Along the way a set of barriers was encountered. In the reasoning of the practice in focus above, and the impediments experienced, several systemic features appear to manifest themselves. This section integrates the analysis of chapter three with the analysis of this chapter in order to identify the persistence of problems and unravel the mechanisms of reproduction.

The first feature that manifests itself in the analysed practice is standardisation. The institutionalised version of standardisation is relevant for the medical practice both in terms of allowed time per consultation and standardised diagnosis-to-treatment pathways. A prerequisite for standardisation of practices is classification: one of the main concerns of both the patient and the professional is to determine a diagnosis. In other words, a classification of the patient and his/her defect is needed to decide on further action. In the case of medically unexplained physical symptoms, no univocal classification based on medical standards exists — the classification ‘unexplained’ itself is contested (Van Dieren, 2007). This leads to a series of problems, like insecurity of both patient and professional; lack of acknowledgement of patients’ problems by practitioners, as well as by family and friends; impaired interactions between patients and subsequent health care professionals; and negative implications for the ability to work and social
participation (Van Dieren, 2007). Most visibly, the mechanism of classification leads to an endless diagnostic trajectory, delivering a chronically ill patient with MUPS.

These problems are entangled with a second systemic feature. As stated, medical rationality is not the clear-cut terrain of medical profession alone; a feature framed as protoprofessionalisation. In the case of MUPS, this feature plays an interesting dual role. First, the patient is inclined to turn to the medical system for help for his or her problems. In doing so, he or she focuses almost solely on a medical diagnosis. This mechanism is meant to deliver objective proof of the reason of the physical impairments, thereby providing peace of mind. It also places the blame outside his or her self. However, by blaming an external factor, the solution is also externalised, whereas the patient actually has to change behaviour to improve health. It is, however, not the patient alone who propagates this externalisation; people in his or her surroundings consistently suggest different approaches and possible diseases. Changing this way of thinking, this bias in problem solving, is the main problem and first concern of the new practice.

Second, a dual role of this systemic feature shows itself via the internal structures of the head of the neurology department: he himself draws on this systemic resource using his medical authority to win the trust of people. He is aware of the value of his knowledge on purely physical medical issues and he uses this (symbolic) capital to actually turn his patients away from a physiological focus. The reassurance that there is not an undetected deadly disease appears especially needed, because in the successive meetings with specialists to which a patient is referred, he or she can receive alarming, but unhelpful diagnoses.

The new practice, furthermore, tries to overcome and is impeded by specialisation in health care and its mechanisms. First, compartmentalisation of care and the resulting endless referrals are the result of the increasingly specialised focus on subsections of the patient’s well-being, which has obviously been very productive in other cases in health care. A construct like MUPS, in which not only physical, but also psychological and social factors are relevant, is even harder to deal with by a medically specialised system. A series of specialised professionals are unequipped to deal with the intertwined features of the patient’s health that all interact. A multidisciplinary team might help, but was difficult to organise because of the general stance of other specialists in the academic hospital towards this group of patients. Second, existing care arrangements make it difficult for professionals to overcome this compartmentalisation and treat the patient as a whole.

All these features appear to be further formalised and their negative side effects enlarged by the value attributed to evidence-based medicine

77 See also the changed GP-specialist ratio as described in Chapter three.
(EBM). When EBM was introduced, the focus was on medical decision-making, subtly incorporating many factors while looking for a treatment. In the subsequent years, EBM became more narrowly defined in terms of being based on randomised controlled trials (RCTs). This makes it easier to compare outcomes of different studies, but the downside is that RCTs offer few possibilities to solve problems that cannot be fit in such a trial, such as the intertwined mind-body health problems. Yet, the EBM discourse plays an important role in educational programs of medical schools in the western world. It is thus likely that EBM and the underlying methodology of RCTs are part of the internal structures of most health care professionals in the western world, due to the socialisation in this medical world. EBM thus structures the behaviour of professionals. Through the conduct analysis of the head of the department, I learned that, in the case of MUPS, this manifests itself in the endless referrals of patients without a diagnosis. This is because EBM supposes a clear diagnosis before treatment can commence; and if there is no diagnosis, no RCT can be developed. An unclear division between the role of mind and body in illness thus results in no diagnosis, and therefore referrals instead of treatment. This leads, as described earlier, to chronically ill patients and high diagnostic costs.

Interestingly, EBM is present in both the general-dispositional as well as the conjuncturally-specific part of the internal structures of the head of the clinic, which implies two mechanisms. The first because he had been working as a neurologist in an academic hospital, hence his firm believe that all medicine should be evidence-based. The second is because he also feels that if his new practice is going to be successful, he has to validate his treatment by a RCT. He knows that other professionals, as well as his management and insurance companies, expect him to work according to highly valued RCT-supported protocols. EBM thus can be seen as symbolic capital. As a result, EBM structures the behaviour of the initiator of the new clinic for unexplained diseases into reproducing the problems of quality of care and indirectly communal costs: to be able to validate his new care intervention, a medical trial was started, which immediately ran into tough methodological problems. Although EBM leaves room to incorporate context and complexity, RCTs consider the important element of the dynamic and social component of disease to be irrelevant for measuring effectiveness. Overall, in RCTs a bias exists in research design favouring simple causal connections and immediate solutions.

In the case of patients with MUPS, this leads to two major difficulties. First, the interaction between body and mind has not been theorised and conceptualised extensively, making it difficult to design intervention studies. Second, patients basically suffer from bad quality of life, which is extremely difficult to measure before and after the intervention. As a result, it is exactly the main concern of patients that is not incorporated in the dominant research methodology.
4.6 MUPS and the UPP framework

The goal of this chapter was to use the identified features and mechanisms from chapter three to unravel the reproduction of problems. These features and mechanisms are iteratively combined and described in the section above. This section reflects on the findings and difficulties encountered while performing the analysis. It, however, first answers the question of who is to blame.

Professionals, patients, and politicians, like Hans Hoogervorst, often ask who is to blame in the case of patients with ‘vague complaints’. Based on the analysis above, it appears a patient with MUPS does not exist in an absolute sense, but can be seen as the result of a complex interaction between actors, institutions and the material world. A patient thus is a co-construct of the patient, professionals, and other systemically (institutionally) embedded actors, who act out systemic properties. In that sense, no one is ‘to blame’. It appears that a search for ‘truth’ instead of for a solution is part of the problem. The mind-body dichotomy fuelling this search for truth then is a historically grown and cultural division, as described in chapter two, and is a very successful paradigm indeed, but appears to have side effects.

The novel MUPS clinic appears to really overcome this mind-body dichotomy, because physical pain is both the point of departure as well as the target of intervention. The intervention, however, works via alteration of mental processes, with the assumption that this will cure the physical symptoms. This practice thus shifts on the mind-body axis. But not only that, it also propagates a shift on the care-cure axis. Or rather, it tries to overcome the institutionalised division between the two. Even though the intervention is primarily aimed at curing, it used an approach that can be more readily found in care practices. First of all, the patient and symptoms are accepted ‘as is’. Further treatments do not require a classification or diagnosis, which is the common starting point for a curative treatment. Secondly, the focus of the intervention is much more on self-empowerment and recognises social factors, besides physical ones. If medical practitioners, managers, and other actors around the practice are socialised in the paradigm of treating bodily abnormalities, these shifts in quadrants pose a systemic problem for the practice when it tries to validate itself.

This chapter comprises a first application of the UPP framework developed in chapter two based on the conceptualisation and operationalisation of the notion of persistent problems. The operationalisation prescribed an approach to constructing a system through the eyes of an agent. What this methodological approach delivered was insight into the systemic reproduction of the earlier introduced side effects, ironically also through the actions of the novel practice itself. The systemically embedded false dichotomy between mind and body, further formalised by the dominant research methodology and also internalised by patients, leads to agents
overlooking possibilities. The enduring problems of disputed quality of care and high communal costs were reproduced, threatening the sustainability of the Dutch health care system.

This approach, however, needed much more development after the work in chapter two. The basic idea was to do an interview with the initiators and take it from there. This proved fruitful, but in itself gave no real guidance to how the issues that arose could be researched properly. Section 2.4, with further specifications of the steps needed to answer the sub questions, was developed while researching what have now become chapters three and four. The yield of this chapter in terms of lessons on how to apply the method developed has been described in 2.4.1 and further specified in the introduction of this chapter. In general, it seems possible to use the UPP framework to unravel prominent mechanisms of how certain enduring problems are reproduced. The system level, however, was mostly neglected in the first interviews. In the first stage of interviews and participatory research, identified success factors with negative side effects play no visible role. Because of this, it turned out to be difficult to actually build up a story. Where to begin if structure and agency are fluid? A good approach I found was to take ‘time’ as the unchangeable constant and point of departure. Not the practice, the patient, knowledge, the system, or money, but time passing by. Working from there, I described the parable of the practice, and from there the parable of how a non-specific patient with, for instance, undiagnosed discomforts over time in interaction with the health care system, turns into a chronically ill patient. From this, decisive or course-changing elements in the parable were taken, further informed by other stories and the literature. Three distinct levels could be identified: concrete happenings, like a GP ordering a blood test; issues at stake, like the quest for a diagnosis based on patients’ wish for objectivation of their well-being; and underlying factors like standardisation, delivering both the rules for receiving care as well as the resource to answer who or what is to blame for the disease. This iterative bottom-up approach of investigation is further specified in the next chapter in order to allow it to be used as a quick scan method.