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 6: Persistent problems in the Dutch health care system

This dissertation set out to explore why it appears so difficult to solve problems in the Dutch health care system. Problems that have been recognised for decades and that have been the subject of numerous interventions by policymakers, health care professionals, and many others. In chapter one, I took as a point of departure the problem definition that the current Dutch health care system, as many Western health care systems, is considered to be unsustainable. In other words, it is questionable whether the health care provisions that exist now will be available for future generations. This issue of tenability is usually talked about in terms of maintaining and improving availability, accessibility, acceptability, and quality of care. Based on the experiences with a program aimed at improving the care for patients with irritable bowel syndrome, I showed that these tenability issues can also be seen as an optimisation problem in health care. In other words, the problem does not lie in a continuing battle between governmental actors cutting down costs on the one hand, and health care professionals and patients asking for more investment in health care on the other. Rather, the problem lies in the fact that subsequent interventions that have the explicit aim to integrate these separate problem definitions encounter opposition from the same system they are trying to reform. Transition management and system innovation literature teaches us that problems like these are difficult to solve due to systemic components, from which it is argued that problems like these require a system innovation or transition. What such systemic components are comprised of, however, and how to unravel them, has so far been unclear. A common term to frame problems of sustainability in agriculture, mobility, and energy that are difficult to solve is ‘persistent problems’. This concept, however, has so far been rather loosely conceptualised and applied, whereas a better demarcated definition can improve understanding of how this persistence works. In order to investigate problems in the Dutch health care system that, first, threaten the sustainability of the system, and second, appear to have systemic component, a conceptual and methodological framework needed to be developed.

In this chapter, I first reflect on the UPP framework that I developed in chapter two by making use of a set of theories. In developing this framework, I translated rather abstract grand theory from the social sciences to the practical empirical level. The operationalisation was tested and further specified while creating the analyses in chapters three and four. Chapter five began with a further operationalisation and translation to make the method suitable for a quick scan approach. The UPP framework not only structured the research in this dissertation, leading to an answer to the research
question on which coherent mechanisms and underlying features produce and reproduce enduring problems, but is also a contribution in and of itself by providing an answer to the second part of the research question on how persistent problems can be unravelled. I will elaborate on this second part in section 6.1. Section 6.2 deals with the more substantial part of the research question, asking what we can learn from novel practices in health care about underlying mechanisms and features. In section 6.3, I reflect on the findings and relate them to current developments in the Dutch health care system.

6.1 The UPP framework for unravelling persistent problems

Persistent problems are regarded a challenge for sustainability. However, while the concept of persistent problems is widely used in transition management and system innovation literature, it had not been conceptualised extensively. Rather it was used to label enduring problems that appear difficult to solve because they are embedded in the system. This vague definition obscured how this systemic embedding actually works. My premise was that more knowledge about this might help new practices, transition professionals, or policy makers to overcome these problems. By combining the notion of the duality of structure (Giddens, 1984) with the idea that modern societies mostly deal with problems that are the result of progress itself (Beck, 1997), I conceptualised persistent problem as a systemically reproduced negative side effect of a success factor of that system — that is, as an enduring problem in coherence with the mechanisms by which this problem is (re)produced. In this approach, persistent problems represent system deficits, and unravelling them reveals the structural properties of regimes through which enduring problems are reproduced, and, thus, how resistance to system innovations or transitions manifests itself on the actor level.

The question then is how to unravel systemic reproduction. Building on Stones (2005) and others, I operationalised this conceptualisation further by iteratively combining a historically informed system analysis with a follow-the-actor approach for identifying and unravelling persistent problems. This part of the framework consists of three elements: 1) the unconscious, by socialisation internalised way the initiators of the practice see the world; 2) the initiator’s more specific knowledge of particular settings and contexts; 3) relevant issues in the context in which the practice functions. Building on that, the reproduction of systemic factors and their negative side effects can be identified by iteratively combining the analyses with the historically informed analysis. What Stones sees as external structures are, however, much more tangible systemic elements than what I tried to uncover via the historically informed system analysis. This analysis in itself is an iteration between what is identified by the practice in focus as relevant problems and the literature.
Where Stones reconstructs a system ‘through the eyes of an agent’, my method is exclusively focussed on problem analysis, which is the reason Beck is included.

The UPP framework I have developed aims to be a tool, both for (policy) professionals who try to understand why some interventions in health care run into problems, and for other people who want to do a system analysis focussed on reproduction of problems. This method tries to translate — sometimes rather abstract — sociological theories into a series of steps one can take. At first, the exact entry point of the analysis, if one’s aim is to unravel system deficits, was not clear. Therefore, a set of analytical steps was taken that informed and ultimately complemented each other. By combining Giddens, Beck, and Stones, the link was made between negative side effects of structures and how to unravel these structures. Following Stones, it was argued that one can reconstruct a system through the eyes of an agent. The question then is: what agent? The steps of Stones, in other words, needed further operationalisation. I therefore combined this framework with the notion of the projective element of agency, as described by Emirbayer (1998).

This comprises the imaginative generation by an actor of possible future trajectories of action, in which received structures of thought and action may be creatively reconfigured in relation to actors' hopes, fears, and desires for the future. Looking at the projective part of agency of a change agent leads to identifying systemically embedded problems, because this comprises both the insight of an agent into systemic problems — which is why the agent feels a novel practice is needed — as well as insight into the mechanisms by which these systemic problems are reproduced — formulated in ideas about how to circumvent problems concerning the establishment of the practice within its systemic context. A new practice as entry point thus was chosen for two reasons: first, it can show the analyst what problems exist; and second, because of its nonstandard care-solution, the practice is likely to run into the structuring features of the system more explicitly, making it easier to reveal the problems underneath the problems. Agency is visible in where things change, like an altered relationship between a patient and a health care professional, as can be seen in chapters four and five. When agents act, their own internal structures change as a result of the reflection on the effect of their actions. This logically also changes the internal structures of other agents, especially when actions deviate from reproduction of the system. In agency, in the effort it takes to act differently, one can see ‘persistence’; it is there where systemic impediment is encountered. One of the things visible in novel practices is that the alternative approach offered by the practice is not seen as a real alternative, because the underlying logic erodes systemic values. These values in themselves, thus, reflect symbolic capital in the system. Table one gives a summary of the iterative approach for identifying and unravelling persistent problems. In sections 2.4, the guiding questions and approach were further explained. In section 5.1, the guiding questions
and approach were slightly altered in order to create a ‘quick scan’ version of the method. Below I reflect on the developed UPP framework.

<table>
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<th>What</th>
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<td>1</td>
<td>Historically informed system analysis</td>
<td>Literature-based analysis. Focus on enduring problems as described by key actors and analysts.</td>
<td>Overview of underlying success factors with their negative side effects.</td>
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<td>2</td>
<td>Conduct analysis of the new practice dealing with identified enduring problems</td>
<td>Interviews with initiators based on interpretive frames (preferred solutions, accompanying problem definitions, and empirical and normative background theories).</td>
<td>A review of what the practice does, how and why: internal structures of the (change) agent (general-dispositional and conjuncturally-specific).</td>
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<td>3</td>
<td>Context analysis of the new practice dealing with identified enduring problems</td>
<td>Further investigating key issues (support and impediment of the practice) through interviews with other actors relevant for the practice, literature analysis and other (participative) methods.</td>
<td>In relation to step 1 and 2, an answer to the question how the system manifests itself, with a focus on systemic success factors and how they (re)produce enduring problems through the actions of agents.</td>
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Reflecting on the UPP framework, it seems possible to use it to unravel prominent mechanisms of how certain enduring problems are reproduced. In essence, the method is a structured way to perform an informed but inductive research. The approach of the case studies is explicitly bottom up. However, this approach makes it difficult to build up a story. In the first stage of interviews and participatory research, identified success factors with negative side effects play no visible role because they are too abstract to talk about in an interview setting. Writing a story that connects the cases back to the systemic focus of the research is challenging. A good approach I found was to follow the development over time as the first object of analysis. Not the practice, the patient, knowledge, the system, nor money, but developments as time went by. Working from there, it is possible to write the parable of the practice, and then the parable of how a non-specific patient with, for instance, undiagnosed discomforts over time, based on the interaction with the health care system, turns into a chronically ill patient. From this parable, the analyst can reveal, informed by other stories and literature, decisive or course-changing elements. A mechanism of reproduction, thus, includes how the structuring elements determine the outcome of the specific interactions between patient and system. In this manner, three distinct elements can be
identified: concrete happenings, like a GP ordering a blood test; issues at stake, like the quest for a diagnosis based on the patients’ wish for objectivation of wellbeing; and the underlying factors, like standardisation, delivering both the rules for receiving care as well as the resources to answer who or what is to blame for the disease.

An interesting additional value of this method is that it is capable to also show systemic reproduction through the people who initiated the novel practice. It appears this can happen because they are prone to validate the outcome of their practice in terms valued by the current regime. In the case of MUPS the focus on validating the new treatment in evidence-based terms impeded the practice. In the case of Interapy, the focus on evidence-based treatment as part of their medical professionalism led to oversight of possibilities of commercially viable preventive treatment programs. These kinds of insights, together with a better understanding of the structural context the novel practice functions in, can subsequently be used to aid an innovative practice to survive or have broader impact, design new innovative projects, or gain insight on a macro level about which structural adaptations might be helpful to support societal change. This is based on the fourth iterative step of the approach, as described by Stones: the exploration of the possibilities for action and for structural modification allowed by external structures, as well as the constraints and influences imposed upon the agent-in-focus by these external structures.

The UPP framework is of special interest to researchers in the field of transition management and system innovation studies, because even though the tool is developed in the context of problems in the health care system, the conceptual framework is transferable to other domains. First and foremost, because the social theory used is not domain-specific, and second, because in health care problems of sustainability exist that are similar to those in other domains, insofar as that they are the result of the success of the system itself. A limitation when applying this framework is that the identification of underlying success factors can take much time if the literature needed has not been brought together before. However, once this is done, case studies become relatively easy, adding to the existing analysis. Likewise, chapter three might serve as a basis for future analyses in health care research in the Netherlands.

A further description of the operationalisation is however still feasible in order to live up to the explicit promise of the UPP framework as a set of clearly defined steps. The translation of abstract theoretical insights about unravelling systemic reproduction into practical research is not finished, and can benefit from more refinement, even though the theoretical approach already underwent much more development after the work in chapter two. The main idea after the first operationalisation was to conduct an interview with the initiators and take it from there. This did prove to be a helpful starting point, but initially gave little guidance on how to proceed. In general,
a first interview both gives an abundance of information and issues, without clear focus, as well as very superficial insights. This is not exclusive to this approach; interviews in early stages of research generally tend to lack focus when looking back after extensive follow up. The theoretical implication of my approach, however, is that relevant issues can be gathered via this first interview. The only way to reach this goal, it turned out, is to have a very open interview design that relies heavily on 'digging deeper' after an initial problem is detected. The methodology section of the dissertation and the introduction of chapter four describe the interview method as 'semi-structured', which was how I set up the interviews. In hindsight I can say that the most fruitful interview parts were completely unstructured. Only when a problem with a solution became apparent, structure emerged by following the interpretive frames of the actors. A future interview set-up might thus benefit from the inclusion of an explicitly unstructured first part, opening with the basic question what the practice in focus is doing how, before the semi-structured part tries to make sure all relevant issues are dealt with.

Another issue is that the UPP framework that was developed in chapter two assumes that enough data is available to iterate between an actor-guided and a system analysis in order to further investigate recurrent issues. As it turns out, the quick scan based on existing analyses makes this more difficult. The analysis of the primary researcher already dictates the focus, providing little opportunity to uncover information that was not there in the first place. One could say a new set of interviews with relevant actors might solve this, but this obviously transcends the very idea of a quick scan. Interestingly, the dissertation of Dedding (2009) lent itself better to the quick scan than the work of Ter Haar. Not because the quality differs, but because Dedding used a different data gathering technique — participatory action research. She stayed closer to the microscopic details of the care problem at hand, which allowed me, in my study as secondary researcher, to make a better connection between systemic features and how they play out in practice. This led me to believe that a good iterative analysis of systemic reproduction should incorporate thick descriptions, like focus groups, interviews, diaries, and so on, as I did in the MUPS case. The analysis of the case of Ter Haar might be improved by re-analysing the interviews, which is an approach that I will try out in new research.

87 Unpublished. However, a version of the analysis in this book will, with a slightly different focus, be published in a new book of the KSI book series, titled: Towards system innovations in health care systems: Understanding historical evolution, innovative practices and opportunities for a transition in health care (Schuitmaker & Ter Haar, 2013, forthcoming).
88 As part of the CSG (Centre for Society and the life sciences) and BE-Basic (a large Dutch research program on environmental and industrial biotechnology that aims to develop industrial biobased solutions for a sustainable society) project "Dialogue as a tool for societal valorisation of environmental and industrial biotechnology" at the VU University. In this project we re-analyse, amongst others, focus group and interview data from an earlier constructive technology assessment (CTA) project in ecogenomics
A limitation of the UPP framework is that, even though the application of the conceptualisation reveals interesting and unexpected information, the question ‘what are the persistent problems in system x’ has no straightforward answer. Instead, the answer becomes a short story revealing important systemic factors involved in the (re)production of enduring problems in the system under research. In section 6.2, I will answer the question as to what mechanisms and features exist that reproduce enduring problems in the Dutch health care system. When I began this research, I aimed at a bullet point list of persistent problems, but the implication of the conceptualisation is that this is not possible. This conceptualisation thus takes away the possibility to label concrete, tangible, problems as ‘persistent’, as was done in earlier research. On the other hand, it opens up possibilities to actually solve those long standing problems because it includes insight in the how and why of this persistence.

Last, because the iteration showed how systemic problems are linked with daily practice, persistent problems that are identified when using this approach can be seen as more than a singularity. The iterative nature of the approach brings about a more objective stance of what persistent problems might be composed, and is as such meant to lessen the inherent bias in analysis caused by (un)conscious reproduction of the researcher’s existing views on the system in focus. Whereas Rittel and Webber assign wicked problems the trait that actors disagree on what the problem actually is (Rittel & Webber, 1973), the approach introduced here integrates multiple views on problems. This helps to distance oneself analytically from daily practice, while staying closely connected to it. The analysis can be used to empower the agent-in-focus, set up new experiments, or create supportive policies for existing similar practices, and may help change agents to finally overcome persistent problems.

6.1.1 Systems theory and STS

In this research, and in the method I developed, I have tried to connect two lines of scientific inquiry. One is most prominent: by making use of elements of systems thinking, I have tried to both explain why problems are being reproduced and how this reproduction can be unravelled. For this second part however, I tried to take serious the warning of scholars in the field of science and technology studies that departing from a theoretical point of view, such as systems thinking, will overshadow the empirical richness of one’s analysis. In other words, the analyst runs the risk of imposing views on the practice, thus obscuring what actually happens. For that reason, proponents of actor network theory (ANT), a well-known family of theories within science and technology studies, are typically wary of strong conceptualisation and formal

(Roelofsen, 2011) through the UPP framework in order to unravel systemic barriers for novel biotechnological monitoring tools.
Therefore, authors from the field of science and technology studies are unlikely to look favourably at my operationalised model of persistent problems. To understand how things happen, they argue a relational view is essential (Callon, 1986; Latour, 1992; Law, 2009).

Inquiries following the approach of ANT generally do not focus on the properties of people and things, but on what these ‘actants’ become as a result of their position in a network. This relational view thus includes human as well as non-human actors. Such actor-networks are often dynamic and, more importantly, inherently unstable. They can be stabilised to some extent when people, technologies, roles, routines, training, incentives, and so on are aligned (Callon, 1986; Latour, 1992). This alignment, however, is always temporary, achieved through configurations of actors that are ‘black boxed’, in the sense that the actants as well as their configuration have become taken-for-granted (Bowker & Star, 1994: 189).

This way of looking at the world directly opposes the basic goal of my research: to explain why it is so difficult to solve enduring problems by identifying stable systemic features and mechanisms that structure day-to-day action into the reproduction of problems. Law (2009), for instance, makes explicitly clear that realities are created through ‘materially heterogeneous relations and practices’, some of which may be more sustainable than others, but which are never stable. However, he also makes clear that he is mainly interested in how things turn out, rather than why. This in itself reflects the critiques that ANT is inherently unsuited to answer causal questions such as why. The focus is on mapping networks and certain aspects of power, while turning away from the question of causality (Harris, 2005).

ANT cannot answer through whose agency, and enabled and constrained by which social structures, the empirical phenomenon in question emerged, which was exactly my point of departure. I thus had to look elsewhere.

The ANT approach, however, did inspire my follow-the-actor approach. This was also reflected in how I performed my interviews. As described above, my interviews were very open, ready to latch onto issues that arose, without structuring the interviews beforehand. Furthermore, I also literally used a follow-the-actor approach, as I followed professionals and patients around. As described earlier, my way to overcome this dilemma — how to take the warning of ANT seriously, while still focussing on systemic reproduction — was to iterate between sources.

6.2 Persistent problems in the Dutch health care system

The problems of tenability of the Dutch health care system are not only enduring, they are persistent. The Dutch health care system, as most care-provision systems in the Western world, is considered to be unsustainable in its current form. From a government perspective, this problem of sustainability is related to the wider problem of tenability of the welfare state.
Over the last 60 years, the costs of health care provisions kept on growing every year without exceptions. Not only in absolute terms, but also as a percentage of the gross domestic product. From a health care practitioners and care consumers perspective, this growth in costs did not lead to an equal growth in quality of care. In general, there is a problem of diminishing returns. Because a range of interventions in these problems did not have the desired effect, these enduring problems are persistent. Persistence of problems can then be understood as systemic reproduction of negative side effects of success factors of the current system. These negative side effects are, first, the result of the progress of the system itself, and second, reproduced by actors through a set of mechanisms.

Based on the conceptualisation and operationalisation of the concept of persistent problems, the central research question of this research was what we can learn from novel practices in health care about which coherent mechanisms and underlying features produce and reproduce enduring problems. Practices that appear to be rather successful in providing higher quality care, with accompanying lower costs, encounter systemic opposition in daily practice. This section reflects on what the application of the UPP framework for identifying and unravelling persistent problems yielded in chapters three, four, and five. The first step was taken in chapter three, where a historically informed system analysis intended to reveal regime elements involved in the production and reproduction of enduring problems. As such, it pointed towards the rules and resources regime actors use, and are guided by, for solving their day-to-day care problems. These resources and the effects of those structuring features also manifest themselves in novel practices of agents that try to overcome enduring problems. The endpoint of the analysis was a list of underlying features that structure agents to follow certain pathways. Based on the analysis in chapters three, four, and five, the institutionalised version of those features can then be seen as the mechanisms of reproduction. This is not to say the analysis in chapter three yielded a clear description of success factors with negative side effects. The historically informed system analysis led to a listing of sensitising concepts that were used in subsequent case studies.

The system, as we know it, is rooted in the great social problems of the nineteenth century. In reaction to poverty and bad hygiene, a wide range of collective care arrangements were constructed. At the centre of attention was the eradication of infectious diseases. Political pressure groups, like the hygienists, created a context in which governmental parties made an effort to create, now considered basic, facilities like sewers and clean water supplies. Also, the first collective health care facilities were constructed. Where hospitals traditionally were operated by private parties to care for the needy, and not necessarily the sick, now medical cure institutions came into being. This development coevolved with what Foucault branded ‘the birth of the clinic’. Based on progress of science in general and medical science in
particular in dissecting and describing in detail the buildings blocks of the physical part of life, diseases became classified in terms of bodily abnormalities. The central focus of diagnosing diseases thus changed from symptoms to physically discernible deviations. This development marked the beginning of impressive medical achievements, based on the meticulous descriptions of the inner workings of bodies and the resulting standardised health care interventions based on this knowledge.

After the Second World War, the Dutch government increasingly took control of both development and governance of the new care arrangements. The societal partners it helped to develop, however, started to operate more and more according to their own problem definition. As concerns about costs grew, stimulating governmental parties to increase control, the medical profession and insurance companies brought up a series of issues. These issues, or critiques, were voiced and debated in newspapers, policy documents, and scientific literature. A particular set of debates can be seen as directly related to the development of the health care system itself.

These critiques were framed as: First, a reductionist view on health as a purely biomedical issue. Second, the idea that this biomedical knowledge base, together with the health care arrangements building on this, was overreaching, which supposedly led to medicalisation of life in general. Third, a process of medicalisation that is supported and pushed forward by the large care bureaucracies that had come into existence following the successful building of health care provisions by governmental and non-governmental actors.

The reductionist view on health follows the discussion about what health, or the absence of health, actually entails. Commonly, being ill is subdivided into three parts. First, being ill refers to the experienced illness, as the subjective, difficult to measure way of how a disease is experienced in terms of complaints and well-being. Second, being ill is treated as a diagnosable condition based on medical and physiological classifications. This condition usually can be measured by scientific methods, that are perceived as objective, and can be classified as disease, regardless of whether the patients actually feel ill. Last, illness behaviour, or sickness, refers to how the patient reacts to the condition: does he or she stay at home, go to a doctor, or go to work. The debate is whether the current health care system, through its medical and financial structure is not too much focussed on the second form of illness, the allegedly objectifiable disease, thereby ignoring the also relevant other two sections, both in searching for the cause and searching for the appropriate treatment.

This focus is not only prevalent in treatment: we also find it in medical research that is to device new treatments. The assumption about causality that underlies the medical gaze of thinking implies that social factors are not important, only physical factors are, whereas diseases might be the result of a complex interaction between the human physiological being and the
environment. Exogenous determinants (physical environment, life-style, and social environment) interact with personal attributes (genetic predisposition and somatic as well as psychological features). The bio-psycho-social model as described in section 1.1.2 was developed as alternative to the purely biomedical approach but has not become leading.

The reductionist view on health is the direct result of the successful way of investigating infectious diseases with this focus. The institutionalisation of this success, in education (medical students memorise lists of physical symptoms of disease), in financial incentives (surgeons are in the highest income group), and in reimbursement structures (to be reimbursed, an objectified diagnosis has to be made, which is more easily accepted when based on scans or blood values) leaves, however, little room for different perspectives. It is therefore linked to the success factors with accompanying negative side effects discussed in the next sections.

Co-evolving with the medical, medical-scientific, and institutional narrow focus on health as a biomedical issue, this way of perceiving health dissipated into society as a whole and had wider effects. The critiques on the effects of this process are framed as medicalisation. The first effect of medicalisation is that people are turned into needy patients. People are stimulated to worry about their health and check regularly for physical abnormalities, while their tolerance for pain and discomfort lowers, pushing them towards the medical circuit for even minor complaints. Health care has become the more or less exclusive field of government, insurance companies, and medical specialists, instead of something that people do for themselves or each other, leaving also the responsibility for good health in the hands of care professionals. The second effect is that the diffusion of medical knowledge also influences what society sees as 'normal'. In the past two centuries, a broad range of behaviours, from homosexuality to alcoholism, have been medicalised. The focus on locating the genetic precursors or the neurobiological basis, of illness, disease, disability and behaviour, implies that the knowledge base of scientific medicine is more and more used to define the limits of 'normality' and the proper functioning, deportment and control of the human body.

The third fundamental critique attacks the institutions that grew simultaneous with the medical knowledgebase and its practice. The large care bureaucracies, built on medical rationality, rob individual citizens from their capacity to take care of themselves, while making those citizens increasingly dependent of anonymous institutions. In addition, these bureaucracies also lessen the professional autonomy of health care professionals. This also goes for health care professionals that acknowledge, implicitly or explicitly, those critiques. In the next section, the underlying success factors with negative side effects, as were distilled in chapter three, are integrated with the institutionalisation of those factors, and how they manifest themselves in novel practices aimed at solving problems in health care.
6.2.1 Mechanisms and features underlying (re)production of enduring problems

The research question asked which mechanisms and features underlie the production and reproduction of enduring problems and how these can be unravelled. This chapter began with the ‘how’ of the unravelling. This section deals with the substantial ‘how’ of how enduring problems are reproduced. As stated earlier, the most notable underlying problem in health care is that the current care regime is the product of the system that emerged in the context of infectious diseases. Where many people died of a contagious disease or accident, nowadays most people die of general ‘wear and tear’. The specialised focus on cure is, because of its success and accompanying wide range of care arrangements, overshadowing other possible foci that can also be beneficial. The focus on cure is not fit to deal with the epidemiologic and demographic transitions that are also an effect of this success.

Success factors, like specialisation, are by themselves not problematic. Rather, based on the analyses in chapters three, four, and five, it appears that the institutionalised versions of the success factors can be seen as both the producers and reproducers of the negative side effects. Evidence-based medicine (EBM) was developed as a supporting tool. Due to its success, it travelled to places it was not meant to function. EBM was never designed as a management tool, or as an instrument to help decide on funding. In that sense, medical knowledge has been institutionalised, thereby taken out of context. This institutionalisation is the mechanism underlying the persistence of enduring problems.

The question then is how these institutionalised success factors create negative effects in the health care system — what the mechanisms of (re)production of enduring problems look like. Chapter three ended with a set of structuring features that can be seen as success factors with negative side effects: standardisation, specialisation, protoprofessionalisation, and evidence-based medicine. In this section these features and how they manifest themselves in the practices analysed in chapters four and five are discussed.

6.2.1.1 Standardisation

The first feature is standardisation of health care practice, which has led to great successes. Standards have first and foremost been used to rid medicine of quacks and impostors, and have put the human body under the jurisdiction of physicians, nurses, and other officially sanctioned medical groups. The first question that logically follows, is whether standardisation and classification change the human body into something it is not — a standard machine. Not only do people differ in how their social context or diet influences their health, also physiologically the human species knows six billion varieties.
Standardisation of health care thus leads to a uniform treatment of a disease based on a statistical analysis, proving that a significant amount of people benefit significantly from a treatment in a clinical setting. This means that, by definition, this treatment is not suitable for all patients.

This standardised way of thinking about disease diffused into care arrangements that were constructed after the Second World War. The idea that it is possible to objectify patients and their diseases and make them fit the institutions (and not vice versa) underlies all standardised interventions. The way in which patients are being fitted into the system can then be seen as the way in which standardisation manifests itself in practices, or as the mechanisms of reproduction. In the case of the novel clinic for unexplained diseases, this systemic feature manifests itself both in terms of allotted 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 (MUPS), no univocal classification based on medical standards exists. This leads to a series of problems, such as: insecurity of both patient and professional; a lack of acknowledgement of patient’s problems by practitioners, as well as family and friends; impaired interactions between patients and subsequent health care professionals; and negative implications for the ability to work and social participation. Most visibly, the search for a classification leads to an endless diagnostic trajectory, producing a chronically ill patient with MUPS. From the clinic for unexplained diseases, we thus learn about the institutionalised mechanisms that reproduce the negative side effect of standardisation: patients who do not fit the standard are not only deprived of help, in interaction with the features described below, they actually become increasingly ill.

From the diabetes case we learned that standardisation, among other things, made it possible to turn the previously deadly disease diabetes mellitus (DM) into a chronic disease. In this development, disease management became central. However, life style related factors that do not comply with the care that professionals have to offer have been ignored. The overreliance on the HbA1c-standard leaves little room for what actually matters to the diabetic patients (in this case, children) in dealing with the disease in daily life. The mechanism of classification of the children into an object with either a healthy or an unhealthy blood sugar level works against the children’s agency, for example, the agency to define the disease in more than just measurement numbers. At the same time, the standardised application of blood sugar measurement for control of DM puts pressure on the professional to look at this technical part of the treatment, diminishing room for the everyday challenges with which the child is faced. Interestingly, the supply side draws on this feature of control-through-measurement and
develops and markets measuring technologies that promise freedom, thereby fortifying the discourse of control that is built on those standards.

Last, institutionalised standardised health care practices directly opposed the added value of flexibility that the new internet-based psychological health care initiative Interapy offered. Professionals that were eager to implement the new Interapy treatment into their own organisations were impeded by existing structures. Here, the traditional mechanism of classifying a person into either a burn-out patient or a person with stress through the general practitioner directly interfered with the goal of high accessibility of the treatment.

6.2.1.2 Specialisation

The standards described above have been the product of and have been supportive of specialisation. In the construction of an effective and professional health care system, specialisation has led to enormous progress. In the decades after the war, the Dutch government was mainly interested in bringing about sufficient health services. In the period between 1955 and 1970, the system increasingly became cure oriented, specialist, knowledge and technology driven, and with a strong emphasis on hospitals as the place of medical action. This specialisation also had a series of side effects. First of all, overspecialisation may not fit with current demographics. After the impressive success that marked the beginning of the current system, nowadays more specialist cure may lead to diminished returns.

Related to that, in a specialist system, clients are eligible to receive the care health professionals have to offer. If the care provider cannot offer a solution, the patient is referred to another specialist. In that sense, specialisation is an important force in the compartmentalisation of health care provisions; a mechanism underlying the problem of the systemic construction of the patient with MUPS. A medically specialised system can barely deal with a construct like MUPS, in which not only physical, but also psychological and social factors are relevant. A series of specialised professionals are unequipped to deal with the intertwined features of the patient’s health that all interact.

Attempts to overcome these effects of compartmentalisation were, in turn, impeded by specialised arrangements. In the case of the clinic for unexplained diseases, it appears that specialised health professionals are not so much inclined to participate in multi-disciplinary care teams now requested for exactly the reason that their specialty is not easy to integrate with other specialties.

In the case of the care for children with DM, the specialisation in care further diminishes the possibilities for patients and their parents to contribute their (lay) knowledge to the care process. The Diabetes Control and Complications Trial is the institutionalised version of specialised diabetes care.
For meaningful participation, the success factor of specialisation is an impeding factor.

Specialisation also has symbolic value, and real-life effects in the case of Interapy. Because health care is divided in a variety of professions, the criteria of professions are based on professional identity. The embedded specialisation in health care leads to precise value criteria for functions, with linked rules for quality and payment, which is reflected in the internal structures of the CVZ as well as the professionals of Interapy. This, also financially embedded, professional value drove Interapy towards treatment and health care instead of towards work-related prevention courses.

6.2.1.3 Protoprofessionalisation

Medical rationality, with a focus on health as a biomedical issue and its specialised professionals and medical standards, is however not solely the domain of health care professionals. The process of medicalisation of daily life also includes laypeople perceiving health as a biomedical issue. The diffusion of the medical professional way of thinking about health care has been labelled protoprofessionalisation. Already during the early development of the modern health care system, especially during the decades since the Second World War, medical discourse found its way outside the professional realm. Through popular publication by medical experts, conversations by patients on what they had been told by experts, standards of hygiene, and so on, laypeople adopted the professionals’ way of talking about and dealing with their health. This process helped greatly in improving the general health of the population. Protoprofessionalisation, on the other hand, probably makes it easier for laypeople to gain access to professional care. This is because, first, laypeople know how to express their problems as being problems that professional care providers should be able to handle, and second, professionals may be inclined to grant these care requests because they are presented with problems they feel competent to handle. As a result, the demand for professional health care is likely to rise because problems people had anyway are more often and more successfully explained in medical terms and are thus directed at the medical system. It is said that laypeople, although they internalised the medical stance, are nowadays less capable of utilising their own potential to become and stay healthy; they externalise the responsibility for, and the coordination of their care, to professionals. These professionals on their part are, because of institutional arrangements, not always capable of taking up this role.

In the case of MUPS, protoprofessionalisation structures the behaviour of patients, leading to reproduction of the health care problem. 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 diagnosis is perceived to deliver objective proof of the cause of the physical
impairments, thereby providing the patient with some peace of mind. This objective diagnosis also externalises the causes of the physical symptoms and thus the blame for the illness. This, however, implies that the processes that may reproduce the MUPS are disregarded. Thus, by focussing on an external factor, the solution is also externalised, whereas a behavioural change on behalf of the patient is needed to improve health. It is moreover 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.

Interapy encountered this in a highly similar fashion. Much to the surprise of Interapy, an impediment was the reluctance of patients to sign up. It appeared they internalised the professional value of face-to-face therapy. Although therapy through the Internet provided more freedom, a set of patients simply preferred to have designated professionals help them. Furthermore, the idea of taking responsibly for one’s own health, through the propagated practice of written assignments, conflicted with the health seeking behaviour of this group, which focussed on health care professionals taking responsibility for offering a cure. Related to that is that people are not used to pay for staying healthy. This is coupled with how reimbursement is set up; it is reactive without focus on prevention. Staying healthy, in other words, is not rewarded. This helps the reproduction of the idea that a patient is not responsible for his or her own health, but the medical profession is.

In treatment of diabetes mellitus, the discourse of control through the medical interventions of measuring and insulin injection is internalised by all actors involved, including the protoprofessionalised parents and their diabetic children. When a professional asks how things are going, a patient most times replies by presenting the blood sugar values. There is, however, an important difference with the case of care for patients with MUPS, in which protoprofessionalisation plays an almost decisive role in reproducing the illness. In the case of diabetes care for children, many children resist becoming part of the medical discourse. Instead of focussing on biomedical factors, these children try to formulate their problems in social terms. Their parents however do appear to focus on medical interventions to help the children stay healthy, supported by the optimistic message of new technological developments. And although the children often resist the dominant medical discourse, they are at the same time extensively trained in and disciplined by the medical side of the therapeutic plot. One could say that, at their age, children are not yet socialised into the medical discourse. Ultimately however, their voice is weakened by the protocolled diabetes care that favours scientific medical knowledge.
6.2.1.4 Evidence-based medicine

The medical rationality that is present in the features and mechanisms above, has been further formalised by a relatively recent development: the progress of evidence-based medicine. Since the introduction of the term evidence-based medicine (EBM) by the Evidence-Based Medicine Working Group, the concept has become increasingly popular. This formalisation of medical rationality started out as a mechanism of reproduction. This logic of analysing and presenting medical research data, however, became extremely successful over the last twenty years, to such an extent that it now can be seen as a systemic feature in itself.

Evidence-based medicine is the practice of medicine based upon the best scientific data available. It forms the basis for the problem-solving approach. In other words, it is a conceptual framework that professionals and students in the health care sciences use for gathering information, processing it, and attempting to utilise what is most important, relevant, and useful. When 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 fitted into such a trial, such as the intertwined mind-body health problems.

EBM has become a powerful discourse that has strong structuring effects; many actors draw on this feature to inform and legitimise their actions. This discourse as such plays a strong role in educational programs of medical schools, particularly in the western world. It can be said 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 education within or socialisation in this medical world. EBM thus structures the behaviour of professionals. Through the conduct analysis of the initiators of the clinic for unexplained diseases, 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; if there is no diagnosis, no RCT can be developed. For professionals, like GPs, this means that a clear diagnosis has to be made before any treatment can commence. An unclear division between the role of mind and body in illness thus results in no diagnosis, and therefore referral 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. The first is because he has 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 believes that if he wants his new
practice to be successful, he has to validate his treatment by a RCT. The clinic’s initiator knows that other professionals as well as his management and insurance companies expect him to work according to highly valued RCT-supported protocols. Insurance companies tend to reimburse only EBM-validated treatments, and policymakers rely on EBM as the guardian against inefficient deployment of health care provisions. Pharmaceutical companies defend the rationale of EBM because the underlying methodology is linked to the production and accreditation cycle of their products, while it excludes health care interventions that involve treatments that are not easy to break down into single blocks with univocal cause-effect relations. EBM thus can be seen as symbolic capital. As a result, EBM structures the behaviour of the initiator of the novel 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 initiated, which immediately ran into tough methodological problems.

In the case of Interapy, the same kind of systemic reproduction comes to the fore. The initiators have a focus on scientifically validated, medical professional interventions that are acknowledged as such by the relevant institutions, thereby overlooking alternative possibilities. In the case of Interapy, the opportunity is to fulfil a much appreciated role as preventive care provider for corporations. Underlying this focus on officially sanctioned treatment is the value attributed to it by the initiators themselves, which may be the result of their socialisation in a professionalised and specialised mental health care system.

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. Thus, exactly the main concern of patients is not incorporated in the dominant research methodology.

The same goes for diabetes care, where life style issues are difficult to bring to the fore in consultations. The institutionally embedded evidence-based treatment options dictate what treatment is reimbursed, leaving little room for meaningful participation.

EBM might thus have become more than a tool to promote sensible and cost-effective care; it has become symbolic capital, bound to institutional positions, and, therefore, used as a resource for other purposes than what it was developed for.
6.2.2 Overcoming persistent problems

By applying the UPP framework developed in chapter two, it was revealed how enduring problems of rising costs and problems of quality of care are reproduced. It appears that the model of disease, called biomedicine, in cooperation with the state-supported care arrangements, has led to great successes, but that its dominance, in the way it institutionalised, also has negative side effects. The systemically embedded artificial dichotomy between mind and body, further formalised by the dominant research methodology, also internalised by patients, leads to agents overlooking possibilities, interestingly enough, including the change agents themselves. Consequently, the enduring problems of disputed quality of care and high communal costs are reproduced, contributing to problems of sustainability of the Dutch health care system.

The process of unravelling of the identified persistent problems through the UPP framework can provide support for a transition in health care on multiple levels. First, because the analysis stays close to the daily practice of the change agent (it deconstructs the daily practice, so to say), the structural factors that are unravelled can be directly used to help the practice function on the niche level it is at now. For instance, the notion of protoprofessionalisation and its mechanism of self-objectifying can inform practices on how to better deal with this phenomenon. As the initiators of the new clinic for unexplained diseases figured, the medical discourse itself can be used to draw patients away from it. Second, the outcome of an analysis through the UPP framework can inform policy makers to change factors at the regime level. New policies can create room for practices that address the features and mechanisms of reproduction. For instance, the managerial quality assurance mechanisms based on evidence-based medicine can be redesigned to leave more room for practices that support the patient as co-producer of care. This is mostly an administrative issue. Furthermore, new evaluation methodologies can be developed to support practices that have interventions that are difficult to prove effective with a standard RCT. The third level is the landscape level. In medical schools, and this transition is already taking place, the training of the medical professionals can change to become more sensitive to delivery of care, instead of evidence-based specialised cure.

89 The EMGO+ (http://www.emgo.nl) institute is a institute that is working on alternative evaluation methods.
6.3 Cure or dare

The underlying idea of persistent problems is that they indicate that a system innovation or transition is needed to deal with problems that are threatening the sustainability of the system, and that these problems are linked to the success and, therefore, the cultural and institutional structure of the system. This dissertation argued that current problems are related to an epidemiological and a demographical transition and the accompanying shifts on the axes of care-cure and body-mind. So what can we learn from novel practices for a transition in health care? And how does this relate to the current policy intervention of market driven, or managed care? What emerged from the practices studied in this dissertation is that they all implied that successful care, both in terms of health and cost-effectiveness, needs to give room to, or stimulate, the patient as co-producer of care. In this last section, I reflect on how this concept relates to how the philosophy of managed care might work out in practice.

Recounting, Buetow (2005) argues that care can only be defined as care if there is an interaction between patient and health care professional that is based on equal contribution to the care process and outcome. Both parties bring their own expertise. The medical practitioner brings knowledge about diagnostic techniques, underlying causes of disease, a prognosis, treatment options, and preventive techniques. The patient has expertise about her or his own body, experience living with the disease, knowledge about living conditions, values, and preferences. A reciprocal relationship between practitioner and patient is fruitful for both process and outcome, but is dependent on the amount of room both actors grant each other. In the practices analysed, patients were explicitly part of the care process, thus co-responsible for the outcome of the intervention. The medical professional neither took control based on a medical-physical diagnosis, nor sent the patient away without support. These approaches appeared fruitful.

The institutionalised versions of the features standardisation, specialisation, protoprofessionalisation, and evidence-based medicine and their accompanying mechanisms impede the patient as co-producer in a variety of ways. Standardisation of health care practices, based on specialised medical knowledge, diminishes the room for patients to include their expertise in the decision process. Protoprofessionalisation does the same in a rather counterintuitive way. The term might suggest that the patient has more tools to communicate with the professional, thus improving the agency to incorporate the personal experiences. However, protoprofessionalisation turns the patient towards the same features and mechanisms, actually lessening the importance of more social influences. Last, evidence-based medicine as a management tool further enhances the effects of these features.

It appears that market driven care interacts with those features and mechanisms in a way that they are reinforced. Market driven care as
philosophy aims for transparency and free choice of patients to opt for the highest quality for the lowest costs. Transparency as practice, however, supposes administration. One cannot compare health care providers if there are no uniform outcome measures. This mechanism thus leads to even more standardisation of health care practices and less room for patient involvement. Furthermore, because insurance companies have the same need for transparency, while becoming responsible for the quality of care, evidence-based medicine as management tool is becoming even more important.

From the set illness, disease and sickness, the second one, being the diagnosable condition based on medical and physiological classifications, now offers even more action perspective in relation to the other two. It used to be that, in the education of health care professionals, few tools were acquired to work with illness or sickness. Nowadays, in the case of market driven care, treating the objectively measurable disease also offers more possibilities for reimbursement. On top of that, because of protoprofessionalisation, treating disease is the only treatment patients actually accept.\(^90\)

Related to this, is the issue introduced in section 3.1.7: the demand side follows the logic of the supply side. The notion of medicalisation implies that the reductionist view of health as a purely medical rationality, which is the rationality of the supply side, is also internalised by laypeople, thus the demand side of care. Via this internalisation, or building of habitus, the demand for care is stimulated by the supply side. A more market-based health care system does not attack this problem, but ultimately strengthens it.\(^91\)

Thus, the actual room that can be created to stimulate the position of the patient as co-producer of care, with shared influence and responsibility, appears to be lessened by the current policy strategies of the Dutch government. It seems that, in the government’s attempt to improve availability, accessibility, acceptability, and quality of care, the bureaucratic institutions have, also via institutionalisation of medical knowledge, actually diminished the room for lay experiences in the consultation room. Exactly that what is needed in order to make the current health care system more sustainable, considering the changes on the landscape level, is impeded by the new regime.

\(^90\) This leads back to the preface of this dissertation and the question as to why no medical professional had been able to explain the simple trick of muscle relaxation to me.

\(^91\) This is not to say that market driven care is inherently wrong. It could work very well as steering mechanism. The current implementation of market driven care, however, does not acknowledge the context in which it is implemented.