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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Summary

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 concern is usually talked about in terms of maintaining and improving availability, accessibility, acceptability and quality of care. 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 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.

Persistence of problems

This dissertation explores why it appears so difficult to solve these problems in the Dutch health care system. In chapter one the experiences of a program aimed at improving the care for patients with irritable bowel syndrome show 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.

Because a range of interventions in these problems did not have the desired effect, these enduring problems can be seen as persistent. 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. A common term to frame problems of sustainability in agriculture, mobility, and energy that are difficult to solve because of systemic components is ‘persistent problems’. This thesis argues that persistence of problems can 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.

In order to unravel the systemic reproduction of negative side effects the UPP framework is developed in chapter two. This theoretical and conceptual framework can be used to identify and Unravel Persistent Problems and aims to be a tool; both for (policy) professionals who try to understand
why some interventions in health care run into problems, as for other people who want to do a system analysis focussed on reproduction of problems.

Based on this conceptualisation and operationalisation, the central research question of this research is 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, but encounter systemic opposition in daily practice. The insight into the persistency of problems can 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.

**Mechanisms and features underlying (re)production of enduring problems**

The first step of the unravelling of persistent problems is taken in chapter three, where a historically informed system analysis intends to reveal regime elements involved in the production and reproduction of enduring problems. As such it points towards the rules and resources regime actors use and are guided by in 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 is a list of underlying features that structure agents to follow certain pathways. How the features manifest themselves in daily practice and the mechanisms by which they do so is unravelled in chapters four and five.

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) is developed as supporting tool, but because of 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.

**Standardisation**

Standardisation of health care practices 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 touniform 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 in chapter four described 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, like 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 for 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 learn 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 the child is faced with. 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.

**Specialisation**

The standards described above have been the product of, and 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 receiving 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, which would have offered financial stability.

**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 deal with, and second, professionals may be inclined to grant these care requests because they are presented with problems they feel competent to deal with. As a result of this, 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 one’s 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, also the solution is 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 their 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.

**Evidence-based medicine**

The medical rationality, and its institutionalisation, that is present in these features and mechanisms, 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, because of 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 we 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. An unclear division between
the role of mind and body in illness thus results in no diagnosis, thus 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 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 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. 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 started, 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 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.

**Overcoming persistent problems**

By applying the UPP framework developed in chapter two, it is 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. 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.