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 5: Systemic reproduction in differently situated practices

In the case in the previous chapter about the novel clinic for patients with medically unexplained physical symptoms, a set of structuring systemic features manifested itself, reproducing problems of costs and quality. The iteratively combined analyses of chapters three and four revealed the mechanisms of reproduction. Furthermore, a set of care issues appeared relevant in terms of systemic reproduction of enduring problems. To expand the analysis as made based on the MUPS case, this chapter adapts the UPP framework to do a quick scan of how novel practices are impeded, and analyses two cases through this framework. Based on the outcomes of the two quick scans, this chapter further explores how and why enduring problems in the Dutch health care system are reproduced by linking the outcomes with the issues that have arisen in chapters three and four. This chapter thus has three goals. First, it investigates whether identified structuring features and care issues are also relevant in differently situated practices — however within the same group of (institutional) arrangements. For this goal, the method is applied to two cases that are not based on first order empirical research, but on the analyses of these cases by other researchers. These analyses are supplemented by literature research. The second goal of this chapter is to show that the method can be used as a (policy) tool to investigate, for instance, optimisation problems in health care. For this purpose, third, the UPP framework is further specified.

The first practice that is analysed is an intervention study into care for chronically ill diabetes patients; the second is a novel practice that offers psychotherapy through the Internet. These cases, like the MUPS case, implicitly or explicitly try to shift on the axes body-mind and cure-care. As explained in chapter one, movement on those axes is central to the kind of issues with which the current system has to deal, compared to the issues with which it was designed to deal. The three novel practices implicitly acknowledge that these new landscape circumstances put pressure on the current regime. First, MUPS are both mental and physical. As in ‘traditional’ practices, the aim of the intervention of the new practice is to cure physical complaints, but the route taken is through mental care. Second, diabetes has both mental and physical elements. A cure has been hoped for since the identification of the disease and expected after the discovery of Insulin. However, a cure has so far been impossible, making all interventions care-related. Even though the disease has mental and physical elements, regular treatment is mainly concerned with monitoring the physical part. The main goal of the diabetes intervention described in section 5.2 is to bring the value of acknowledgement of social factors to the fore. Third, the novel practice
Interapy is explicitly aimed at the cure of mental problems, but in its approach, it does include care for physical factors. All these practices somehow try to overcome institutional and cultural boundaries concerning cure-care and body-mind in order to improve availability, accessibility, acceptability, and quality of care, and encounter systemic opposition in doing so.

The first case that is analysed through the quick scan version of the method developed in chapter two concerns a project based on participatory action research by Christine Dedding. She investigated diabetes care for children; how their personal experiences and knowledge about (dealing with) the disease are largely ignored by health care professionals. Her assumption is that especially these are relevant for high quality care. Her intervention was based on seeking ways to create room for children to participate in formulating the problem definition and the subsequent course of action in the care process.

The second case is a new practice in mental health care that developed psychotherapy via the Internet. This practice has been investigated and described by Erica ter Haar as part of her research about impact and the role of power in relation to a (possible) system innovation in health care. Interestingly, although this practice did not depart from identified problems, the same underlying issues as identified in chapter four impede its success.

5.1 Quick scan for unravelling systemic reproduction of problems

As argued in chapter two, a persistent problem can be seen as a systemically reproduced negative side effect of a success factor of the system in focus. The negative side effect is an enduring problem, as described by a researched practice in focus, as well as in the literature. I proposed five guiding questions as a method for analysing these system deficits. This method is aimed at analysing the structural properties of regimes through which enduring problems are reproduced — and thus resistance to change is effectuated. In this section, I develop the method further to make it possible to do a quick scan, without an entire system analysis. Because the quick scan follows the same analytical framework for doing a system analysis as the full method, the results of those analyses can also be used for the overall system analysis in this dissertation.

Essentially, and in terms of theoretical basis, the method stays the same; systemic reproduction of problems can be unravelled by iterating between (literature) research into relevant care issues and research into the premise, expectations, and experiences of a practice aimed at solving identified problems. Question a) of the method as described in chapter two, however, has to be adapted to serve the goal of a quick scan. In the version as presented in chapter two, this question directed the analyst towards
historically embedded sensitising debates. In chapter three, I described a
genesis of the current system to identify relevant regime actors and regime
factors, leading to a description of more fundamental systemic features. This
would however be too extensive for a quick scan. The goal of a quick scan
could be to support new practices solving current problems, not redesigning
the system as a whole. Furthermore, the policy horizon of a policy adviser
probably is no further away than a couple of years. The first guiding question
thus has to aim for less historic and more current, practical problems. The
outcome of the analysis can then be directly used to help the new practice or
similar practices to overcome barriers when solving pressing care issues.

This is not to say that such an approach would not also contribute to a
system innovation or transition. In the first place, the quick scan is still
connected to systemic problems via the concrete problems recurrently
identified in policy papers and reports from the field. The focus shifts from
underlying features in terms of success factors with negative side effects to
debates about widely discussed issues in the care for a particular (group) of
disorders. These debates, however, also incorporate ideas about underlying,
more systemic issues. The analyst can reconstruct the link with success
factors with negative side effects, if desired. Second, the outcome of the quick
scan can be used to support a couple of eye-catching new practices by
designing supportive policies for these practices, which will also implicitly
support related practices, and, as such, transition movements.

The first step of the quick scan, related to part one of the method,
would then become a short literature review about the disorder, or group of
complaints, in focus — in contrast to a literature review about the system in
focus. With this, as well as the other questions, the focus is on the
arrangements around the disorder under scrutiny. The five guiding questions
then are:

a) What care issues are prevalent in debates around the disorder in
focus?
b) How does the new care practice in focus organise itself; what
solutions fit what (care) problem?
c) Premise and expectations underlying the practice; how does the
current (health care) system deal with the disorder?
d) What kind of support or impediment does the practice experience; like
financial, managerial, organisational, non-cooperative colleagues or
patients?
e) What, if any, is the link between issues brought up in the literature
(question a), how the practice tries to overcome this (questions b and
c), and how the practice is supported or impeded (question d)?

Although this slightly trimmed version of the method is a quick scan, it still
has to be iterative. As explained in chapter two, the questions cannot be dealt
with in a purely linear way in time; the researcher has to go back and forth between questions. Although the general approach to answering the questions, as presented in chapter two, can still be used, some specifications and slight alterations can be helpful.

Question a) is answered for both cases by searching literature dealing with the disorder in focus on a more aggregate level, on an epidemiological or policy level. These are reports from, for instance, governmental agencies like the RIVM, some publications focussed on patient care (including some information about alleged biomedical causes of the disease), or publications of patient advocate groups. This question is dealt with in the main introduction of the case in this chapter.

The questions b) to d) are the guiding questions for the first three subsequent sub sections of the case. For these questions, other research describing the practice has to be available in order to do a quick scan. As described in section 2.2.3.2, the point of entry is the problem definition of the novel practice. The first action, therefore, is to read the documentation available and identify the four layers of the interpretive frames. While reading, some issues appear to be important and arise repeatedly in both the point of departure (internal structures of the agent) as well as at important moments in the development and current workings of the practice (external structures). Since issues evolve in interaction between the internal and the external structures of the practice in focus, the iterative element of the method works via further investigation of these issues. Question b) still focuses exclusively on the problem definition of the practice, which basically asks what the practice actually does, departing from the perspective of the practice on how identified problems can be solved. I approached this by describing a short history of the practice: what the practice is doing now and how it got there. This story usually entails multiple consecutive solutions for problems, in the sense that multiple obstacles had to be overcome, some obstacles being the side effect of an earlier solution. This is a factual account with as little analysis as possible. I supplemented reports and other documentation about the practice with an interview or two with the initiator or the author of the analysis.

Question c) is answered in the same way as in the method described in chapter two, by further researching the underlying rationale of the problem definition of the practice in focus. In the information gathered for question b), a set of (recurrent) issues in both the point of departure and in important moments in the development and current workings of the practice is visible. Around these issues, other actors, with their own problem definition, interact with the practice. Structure manifests itself via the actions of agents and thus in issues that show up recurrently. This question can thus be answered by elaborating on the issues, describing the underlying reasoning of the practice in focus regarding these issues and their nature. It is important here that all issues are approached from the perspective of the practices.
Question d) departs from prevalent issues relevant for the functioning of the practice that emerge from questions b) and c) — the issues that arise recurrently in the history of the practice. These issues, being impeding or supporting, can be further investigated with a focus on the role of other actors in the manifestation of these issues and the problem definition underlying the actions of those other agents. The motivations of these other agents in the arrangement of the practice are mostly described in the documentation already gathered.

When saturation is reached regarding information relevant for the functioning of the practice and how it is supported or impeded question e) is answered. In a number of the issues described as part of the answers to questions b), c) and d), the (underlying) problems also found while answering question a) are to be prevalent. Reproduction of systemic problems can be found if issues recur and connect in a), c) and d); in other words, in both the wider debates around the disorder, the particular reasoning underlying the new intervention of the practice, and in how and why the practice is impeded or supported, based on the motivations of other agents. Here the researcher thus analyses if and how underlying structure (comprising for instance financial and legal rules or cultural elements) manifests itself in the practice in focus. This manifestation can also occur through the actions of the change agent himself, who might unintentionally and unconsciously reproduce systemic features. The two sections 5.2 and 5.3 follow the structure of the five guiding questions.

5.2 Reconfiguring diabetes care for children

The precise prevalence of the chronic disease Diabetes Mellitus (DM) is not known. In 2000, the total number of people with diabetes in the Netherlands was estimated at 462,000. More importantly, it was stressed that incidence is increasing (Bakker & Bilo, 2004). According to a RIVM-report (2005), the number has grown to 600,000 in 2003, and to 740,000 in 2007 (Baan, 2011). Because of the growing attention for the disease it is however possible that patients who carried the disease without being aware of it, had by then been diagnosed. Still, it is estimated that on top of these numbers, between 200,000 and 250,000 people have diabetes, without being aware of it. In 2007, the total costs for diabetes care were estimated at one billion Euros, which was 1.4 per cent of the total spending on health care in the Netherlands. The largest part, 58 per cent, was spent on medicines and care appliances (Baan, 2011).

Approximately 85 per cent of DM patients have type 2 diabetes, and especially in this group the rapid growth is found. In addition to the prevalence, the age of onset of the disease is also changing. Classically type 2 diabetes was associated with older age, normally over 50 years, but now more and more children, and especially adolescents, are diagnosed with type
2 diabetes (Ramchandani, 2004). The increase is thought to be related to the increase in obese people, since risk factors comprise, besides genetic predisposition: overweight, lack of physical exercise, smoking, and dietary habits. Especially a high intake of saturated fat and a low intake of fibres are thought to be related to type 2 diabetes (Baan & Poos, 2005). The insidious onset of this variety makes Diabetes Mellitus type 2 (DM II) a severely under-diagnosed disease. Often when diabetes mellitus type 2 is diagnosed, complications are already present (Ramchandani, 2004).

In children, type 1 diabetes, together with asthma, is the chronic disease with the highest incidence. The prevalence of DM type 1 (DM I) is about 0.5 per 1,000 for boys, and 1.8 per 1,000 for girls in the age of 0-14 years old. Every year, 560 children in this range are newly diagnosed. DM I is the result of the breakdown of insulin-producing beta-cells in the pancreas. Patients have to inject the hormone several times daily in order to regulate their blood sugar level. Injecting can be done with a kind of fountain pen with a needle. Another option is an insulin pump, which is roughly the same size as a small mobile phone. For patients with DM II, sometimes taking pills is sufficient (Dedding, 2009).

DM however is not a matter of just an artificial intake of insulin. It is a metabolic disorder, and thus a dysfunctional system. All factors in the system, like genetic predisposition, current lifestyle, or health history, are relevant. Focus on just one symptom does not cure the disease, nor is it likely to produce meaningful health management (M’charek et al., 2005). As explored in chapter three, one of the critiques on current health provisions, is the focus on the biomedical part of disease, ignoring other factors. Possibly as a result, many patients perceive their health as being of low status. Furthermore, especially young patients express complaints of fear and depression.

When looking at the process of care for this growing group of patients, blindness, kidney failure, amputations of limbs, heart failure, and atherosclerosis are all complications that might occur in the life of a diabetic person sooner or later. This depends on how well they keep control over their blood sugar. Control thus is an important issue, also in the contact between patient and physician (Freeman & Loewe, 2000). However, the chance to die directly as a result of a badly regulated blood sugar level is small, because of the well-developed equipment to check and regulate. Thus, there is a discrepancy between successful short-term interventions and long-term risk, which makes it difficult for patients to follow the regime professionals formulated (M’charek et al., 2005).

Besides these more psychological and socially embedded difficulties in gaining control, hyperglycaemia itself is a contested concept. Although there

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clearly is a link between blood sugar regulation and insulin, the exact mechanisms might differ between patients. Gender, ethnicity, and the social context in general influence the occurrence of a hypo (M’charek et al., 2005). In other words, a patient does not function as a machine with fixed properties that can be tweaked by standardised health care interventions.

The Dutch Diabetic Federation (NDF: Nederlandse Diabetes Federatie) tries to promote multidisciplinary and patient centred care in which education of the patient, and involving the patient in caring for their disease are important elements. Different studies, however, show that implementing this kind of care is not a straightforward task. It is suggested that this is related to the specificities of diabetes care; whereas the health care system is traditionally organised around acute and episodic illnesses, diabetes is a complex multi-systemic chronic disease (M’charek et al., 2005).

The value of the patient as co-producer of care has repeatedly been suggested. In the past, consultations were regarded as transactions between active providers and passive consumers. It is now recognised that patients supply at least 85 per cent of the information required for diagnosis and that their participation and understanding are essential for management of the illness. Furthermore, it might be necessary to build a personal relationship between care professional and patient on which continuing mutual responsibility can and should be built (Hart, 1992).

The practice in focus in this section is an intervention study that was done by Dedding (2009), focused on improving care for children with diabetes by interactively exploring the value of more patient participation. The underlying assumption is that the larger part of treatment is performed by the patient, in his or her own social environment, and not by medical professionals in hospitals. For adequate treatment, the problems patients encounter in this environment have to be addressed, and not the physiological problems alone. Dedding explored patient participation of children with diabetes by, first, researching how children perceive the delivered care and what problems they encounter, and second, by devising and carrying out an intervention together with a group of children to get their voice heard. This resulted in new means of communication in which children voiced their experiences: a rap-song, an educational DVD, and a book. On the basis of her data Dedding describes four ways in which meaningful participation is impeded. The first and most important way is the cultural and institutionalised focus on control of the disease. Intertwined with this discourse of control is the low status of tacit knowledge while obtaining control, which is linked to how patients in general, and children in particular, are perceived. Last, the idea that especially new technologies help improve care is described as an impeding feature. The focus on control is reflected in the therapeutic plot that is constructed by professionals, patients, family members, and health technology companies involved in the care for diabetes patients. This plot is focused on the possibilities of leading a healthy, happy, and (care) free life,
in which the hindering disease is under control with the help of new tools. But exactly this therapeutic plot diminished opportunities for children to participate meaningfully, which, according to Dedding, decreases control.

5.2.1 The practice; solutions for what care problem

To look at what solutions fit which problems and at what Dedding has done to develop and implement possible solutions, I departed from her dissertation *Delen in macht en onmacht: Kindparticipatie in de (alledaagse) diabeteszorg* (2009) (Sharing in power and powerlessness: child participation in diabetes care), which describes her participatory action research in detail. This story became more structured and was supplemented by a number of conversations in which Dedding and I discussed both her and my analyses, and by further research into biomedical as well as social literature regarding diabetes care.

The primary interests of Dedding are power, participation, and (the needs of) children. The point of departure of her intervention study is that patients, with the focus on children in this practice, experience a lack of opportunity during contacts with professionals to communicate their knowledge and life experience about how to deal with the disease. There either is no time, or the professional does not want to hear it. At the same time, doctors work passionately for the children to get the disease under control, but they often feel at a loss when nothing appears to work. Furthermore, the parents are responsible for their children, but have trouble helping them control the disease and fitting their child’s disease into the desired ‘normal’ family life. As a result, patients, professionals, and parents at times feel powerless while trying to get the blood sugar regulation under control.

Dedding’s primary goal was to research these issues. After a pilot study, she concluded that children felt they are not acknowledged as individuals and ‘hands-on’ experts. In essence, the children stated that, even though they do the same work as a health care professionals, they are being treated as children. The children said that they performed complex medical acts, but then were not taken seriously in the doctor’s office as a conversation partner. A complicating factor is the fact that a consultation with a diabetic child is not a matter of two, but of three main parties, because the parents are heavily involved.

The pilot study showed, furthermore, that the perspectives of children and practitioners differ at essential points. Most practitioners, for instance, described the needle-prick for measuring blood sugar levels as more painful than the insulin injection, because of the high density of nerve-endings in the tip of the finger. Most children say it is the other way around. On top of this, practitioners, as well as parents, appear to be largely unaware of, first, the fact that children actually have their own ideas about, for instance, the cause, the symptoms, and the treatment of the disease; and second, that these
ideas have consequences for how children experience the treatment and whether they comply to it.

Dedding concluded that because there is not enough knowledge about the perspectives and experiences of children, the treatment cannot be adjusted to their social environment. This makes it not only more difficult for children to adhere to the treatment regime, but adds to the problem that children are on their own when translating medical treatment prescriptions to their daily life.

To act on the conclusions and look for ways to improve the situation, Dedding continued by participating in health care interventions, and, later on, by intervening herself. Based on the idea that such research can be done best in cooperation with the children in focus, Dedding invited the children to be not only informants, but co-researchers. The central question became how (not if) participation can be meaningful.

Dedding invited children with DM I, between the ages of eight and twelve, from three hospitals in Amsterdam, to first, collectively define what the core problem is, second, to design an intervention for this problem, and third, to evaluate this intervention with fellow-sufferers in two hospitals outside Amsterdam. She began by approaching children in the waiting room with the message that ‘no one knows how it is for children to have diabetes, besides the children themselves’, after which she asked for consent to follow the child to the series of appointments with practitioners. She also interviewed the children later on in the trajectory, as well as practitioners and parents. Thirty children agreed to be followed. During the research, the level of participation of the children grew. Children developed plans for interventions themselves, did participant observations in, for them, unknown hospitals, prepared and held interviews, and set the methods for the evaluation.

When after a series of interviews and smaller focus groups, Dedding organised a first larger group meeting, the children as a group denominated ‘lack of understanding in the environment’ as the core problem. Dedding pushed to specify who and what, but the children insisted the environment included everyone. Based on this, the children suggested three interventions to attack this problem: a movie, a TV-commercial, and a book. Dedding arranged workshops on acting and film-making. Regarding the first intervention, the professionals involved doubted the practicability of making an entire movie. This problem, however, disappeared when the children met a rapper in the studio they had the workshop in. This inspired the children to make a rap song with accompanying video-clip instead, including a ‘making of’. Stichting Artsen voor Kinderen (Foundation of doctors for children) agreed to finance the rap-video and the making-of, provided the final DVD included an educational video of their (and not the children’s) making. For the second intervention, the book group, Dedding arranged a writer to give a workshop. This writer was enthusiastic about the project and offered to help write the
entire book. This did not appeal to the children because they were afraid the
writer would take over the project and undermine the children’s effort to tell
their own story. After a number of conversations between Dedding, the
children, and the writer, this issue was solved. Financing the book, however,
required more lengthy conversations. Publishers had to be convinced that it
would become a book of high quality, even though there was no official adult
supervisor. Furthermore, the fear was the book would not add to the already
existing material. The book was published in November 2008. The third
group, working on a TV-commercial, was eventually merged with the film
group for purely pragmatic reasons.

Following the participative approach in the development of these
educational materials, the children were also involved in the implementation
and later analysis. Several local and national TV programs reported on the
products and showed the clip, but more important is the local implementation
by the children themselves showing the rap to their ‘environment’. Furthermore,
based on the research done by the children in cooperation with Dedding, a teaching package was developed, so that the school, an important
part of this ‘environment’, could be informed about what life with diabetes
really is like. Last, the children presented and discussed their formulated core
problem and accompanying intervention with diabetic children in different
hospitals.

An interesting reaction from some parents, especially to the book, was
that it was too negative. Parents appeared to want to maintain a positive
image of living with diabetes and how everything is still possible provided the
children complied with the treatment protocol. The children were not
impressed by the critique and reacted by stressing that the reality is not that
nice, and one child said that this was good because it showed that the parents
finally listened. All in all, it appeared that the parents of the children were
confronted with how their child experienced the disease in a new and
insightful way. This also appeared true for the practitioners involved. Several
care professionals expressed how the project helped them reflect on their way
of dealing with children. Allowing the children define what the problem was
(their point of view has not been heard), and how to engage with this
(produce a rap-song with a video clip and a book), and develop, in a
participative manner, an intervention that stimulates the active involvement
of children in the treatment of diabetes mellitus, appeared to result in a better
fit between treatment advice and the social environment of children. Part of
this process was to show that a child’s perspective actually exists and that it
is relevant. To make this possible, Dedding aimed to show what cooperation
can yield, how it can be reached, and what factors work against it. For
participating in decision-making you need to be able to argue your point of
view. This is what the practice tried to create.
5.2.2 The practice; premise and expectations

According to Dedding, getting the disease under control is the most important goal for both children and health care professionals. However, both groups perceive control differently. The assumption of professionals is that knowledge and awareness of risks results in good decisions and behaviour. The children are aware of these risks, but in practice children experience problems in daily life that they consider more important than a future no one can predict.

In theory, diabetes as a medical syndrome is controllable. But in reality, sufficient control is almost never reached. In the clinical setting there is a lack of knowledge about and attention for living with the disease, as well as the perspective of patients. This not only leads to practical problems, but also can frustrate patients and care givers. Insight in the social environment of patients is necessary for attuning the medication and treatment options.

Knowing and taking into account the social environment is necessary, because most of the day-to-day treatment is done by the patient him or herself; outside the hospital and the reach of medical professionals, at home, or at work. In the case of the study by Dedding, treatment is mostly performed by parents and children. A medical team, consisting of a paediatrician, a specialised diabetes nurse, a dietician, and a child psychologist, evaluates the child’s condition on average every three months. The team prescribes treatment, coaches the child and parents, and gives education about the disease and physiology. It is the responsibility of the parents and the children to incorporate this knowledge in daily life through: 1) attuning insulin injection to composition and amount of food and moment of intake; 2) measuring the blood sugar level multiple times a day by means of sampling blood with a small needle; and 3) take influences like (physical) exertion, stress, and infections into account while doing so.

Because this approach to treatment does not appear to yield the desired effect (control), children have a feeling of failure. When meeting the care professionals, they feel as if they are subjected to an oral examination. The doctor will say ‘things are not going well’. The child knows that, but the child’s problem of how this can be improved by concrete actions in daily life is not on the agenda.

To improve this, children need to be treated as an equal partner in both the decision process and the care trajectory, so children acquire better tools, and learn how to deal with their disease, to prevent complications in the future. According to Dedding, children, first, possess knowledge and experiences unique to their situation, where parents are not reliable representatives for the child perspective, and second, children want to share these experiences and participate in the decision making. In fact, the children are the real experts on how to cope with diabetes in real life. However, children are usually seen as passive receivers of care, while they have the feeling they have to do work — that is, medical action is not limited to the
health care professionals. This lack of voice is not only prominent in clinical practice; medical treatments in general are usually attuned to adults.

Besides better decisions on what care path should be followed, participation then also leads to better compliance to the care interventions agreed upon. This is, first, because the outcome fits the needs and wishes of the target group better, and second, because people support policies in which they have been involved and for which they feel ownership more easily. The idea exists that children are too young to participate fully, but several studies have shown that children are capable of processing complex and often very painful information. Young children can make very wise decisions, provided that the necessary information is presented in a clear but considerate way.

Based on literature research, Dedding defines meaningful (also called sincere, active, or effective) participation as participation that has influence and leads to changes. Redistribution of power is an essential element for incorporation of the perspective of the patient into the process of decision making. The distribution of power is not only dependent on the point of view of a single medical professional, but on the structure of and processes in the health care system. Dedding then states that meaningful participation can happen in a context in which cooperation between patient and care providers is based on incorporation of multiple fields of expertise, which is a notion also framed as ‘the patient as co-producer of care’. 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 his or her 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.

Dedding took the philosophy of participation as starting point for her research both in terms of unit of analysis, as well as method. Participatory research methods have been used since the seventies, mainly in international development projects, as a response to, first, the failure of top-down approaches, and second, the conventional paradigm in social science research which sees research as something that can only be done by experts educated in a highly specialised domain. The expert then studies problems of others, with the ambition of objectivity, reached by maintaining distance to the object of research. Critics say that such an approach leaves resources of everyday knowledge unused. Moreover, it is argued that knowledge production has become too much of a goal in itself (Cornwall & Jewkes, 1995). This everyday knowledge is also called tacit knowledge — knowledge that is embodied, for example, how to ride a bike, or knowledge embedded in material or
intellectual contexts. This is relevant knowledge that cannot be isolated, written down, and distributed, but can only be communicated through a socialisation process (Polanyi, 1958). The core of participatory research is ultimately to respect and understand the people with and for whom researchers work — working together towards analyses and solutions — and enabling those whom the research concerns to set their own agenda for research and development, and so giving them ownership of the process (Cornwall & Jewkes, 1995). Dedding made use of methods of participatory action research, which not only aims for raising sympathy, but also for emancipation and action.

According to Dedding, meaningful participation thus leads, by incorporating the child perspective in both process and outcome, and thus their tacit knowledge, to better control of the disease in terms that are feasible for children, parents, and health care professionals.

5.2.3 The practice; support and impediment

Dedding’s goal was to research what meaningful participation is, how it is impeded, and how it can be implemented. She did so by doing interviews and participant observation studies and by designing and carrying out an intervention study together with the children. Dedding thus focussed on the impediment of meaningful participation in both her own ‘novel practice’, and her own research. Given the duality of this quest for application of meaningful participation, this section takes the experiences of Dedding and her research results as one. In this section, ‘the novel practice’ is then understood as the practice in which child-participation in the care process is made possible and impeded and is thus not limited to the pure ‘practice’ of Dedding doing the intervention study. A focus on that practice would lead to a focus on problems of doing research, thereby defying the goal of this analysis, which is to research problems in health care. Either way, we are still following the perspective of the practice in focus, via the person of Dedding, on wider health care issues.

Dedding did succeed in improving the position of children in medical practice and their meaningful participation in the process of daily care. However, this was not a straightforward task. She encountered opposition during her research. This opposition can be seen as impediment that might be expected yet to exist for most diabetic children. Following Dedding’s experiences, one can say that meaningful participation is impeded in four ways: first, the focus on control and how this is done; second, the low status of tacit knowledge while obtaining control; third, how patients in general, and children in particular are perceived; and last, the idea that new technologies help improve care. These ways are reflected in the therapeutic plot that is constructed by professionals, patients, family members, and health technology companies involved in the care for diabetes patients. This plot is
focussed on the possibilities of leading a healthy, happy, and (care) free life, in which the hindering disease is under control with the help of new tools.

The therapeutic plot is a positive story, a story of success. Patients try to keep moving, and they see the disease as a challenge they, as a family, can take up successfully. Part of this is the idea that, even though the child is ill, her or she is still able to accomplish everything. This has a supportive influence on child participation but is also impeding. First, when the child is participating in this discourse, it can provide a sense of strength; to be able to endure the hardships like self-injection of insulin, while being ‘cool’ about it in public. Some children have the feeling they are stronger (mentally), smarter, and more self-sufficient than other children because diabetes teaches you how to take care of yourself. Quality of life studies show that children with diabetes report fewer complaints and stress than healthy children in their age group. On the other hand, when things are not going well, there seems to be little room for children to communicate their problems because of the dominant positive discourse that is (re)produced in daily life. This is why the children in Dedding’s study chose ‘lack of understanding in the environment’ as the core problem they wanted to address. The positive story appears to be important for both children and parents to deal with feelings of loss of control and to keep going; both try to protect each other in daily life against negative experiences. When the children made the book to communicate how things really are for them, some parents were shocked and expressed their concern about the negative tone of the book. The idea that leading a normal life while suffering from diabetes is possible is apparently confirmed and reproduced in daily life in order to keep the spirits high, but the child is also disciplined through it.

The voice of children is also impeded in a more institutionalised way. In this therapeutic plot of success, the medical discourse has a relatively loud voice compared to other knowledge sources. It is written down in books, protocols, and a large body of scientific literature. It is dominant at conferences, in the educational path of medical professionals, and thus in the consultation room. In 1994, a large clinical trial (Diabetes Control and Complications Trial) showed that adequate control of the blood sugar level is possible and that rigorous control reduces the risk of complications. The aim was to keep haemoglobin A1C levels (HbA1c) as close as possible to the normal value of six per cent or less (DCCT Research Group, 1994). HbA1c stands for the ratio of glycosylated haemoglobin over total haemoglobin and can be used as a measure for the average blood sugar level over a longer period of time, as persistent raised plasma glucose levels cause the proportion of haemoglobin to go up. HbA1c is thus seen as an indicator for the risk of medical complications in the future. The test then signifies the average amount of diabetic control over a period, originally thought to be about 3 months (the average red blood cell lifetime), but more recently thought to be more strongly weighted to the most recent two to four weeks. In the non-
diabetic, the HbA1C level ranges from 4.0-6.0 per cent; patients with diabetes mellitus who manage to keep their HbA1C level below 6.5 per cent are considered to have good glycaemic control. The DCCT study grew into an important point of reference of both what is possible and of what is desirable — control via intense therapy and extensive measuring. The study was criticised, among other things, because it obtained its results in a laboratory (i.e. controlled) setting. In a real-life setting, patients quickly experience that more factors have to be taken into account and that control is not that easy. For a medical professional, however, the medical focus has supremacy. ‘Good practice’ for professionals is measured by medical standards: the HbA1c-level dictates what good practice is, backed up by actors like insurance companies or managers, and formalised in treatment protocols.

When control in practice is difficult, the professional may experience failure. Because the body is supposed to react in a well-defined way to well-defined treatments, this failure is attributed to social factors. Such factors are considered difficult to control and, more importantly, outside of the medical discourse. From that perspective, a patient without adequate control of his blood sugar level does not comply with the behaviourural rules that follow from this medical discourse. The professional then feels powerless and frustrated because everything has been tried, while the patient does not comply, which leads to even less room for meaningful participation. The experiences of patients in general and parents of diabetes patients in particular have been researched, and their stories do have a place in the consultation room, but are only marginally present in medical textbooks and conferences. The experiences of children, in particular, are even more difficult to find.

The use of these perspectives in actual therapeutic settings is further diminished through some of the perceptions professionals can have of patients. Based on the literature (for instance (Mol, 2006)) and experience, Dedding mentions six. First, patients do not know what is right for them; second, taking part in the decision process is too much of a burden; third, patients are unable to maintain an overall view; fourth, patients are too emotional and subjective; fifth, patients can ask senseless questions; and last, they cannot represent other patients. For children these perspectives are extended with the idea that children in particular are vulnerable and unknowing. Thus, actual control is very difficult to reach, and the medical discourse in the literature, further extended by possible professionals’ perspectives on patients, marginalises the patients’ personal life even more, simultaneously underestimating the possible contribution knowledge about this life might have.

The discourse of control and leading a happy and sorrow-free life is also reproduced by technological artefacts developed for diabetes patients. Insulin was discovered in 1921. This was seen as a heroic magic potion that saved patients, defeated disease, and ended suffering, thereby strengthening the idea that man was able to defeat any disease. The description of failing
kidneys in 1936, however, led to the realisation that the disease had not been defeated, but changed from an acute into a chronic disease. The focus, as a result, shifted from problems the patient was experiencing here and now, to possible complications in the future, and always from a medical point of view. Furthermore, even though the focus had shifted from curing to fighting complications, the underlying story of success through technological progress remained forceful. Nowadays, new technologies like blood sugar measurement devices and insulin pumps are marketed as devices that help patients to, finally, keep the blood sugar at a healthy level without any effort, making it possible to go mountain climbing, be fit as a puma, or just chill out on the couch with everything under control. This has two important effects. First, while machines may enable better control, their handling exponentially increases the amount of work that actually has to be done. Second, these technologies focus on a healthy blood sugar level only, further diminishing the role of the social environment in which those numbers have to be controlled by a person who is more complex than just blood sugar levels.

Better tools to control the blood sugar level thus do not mean the disease is controlled better. The insulin pump, for instance, has the advantage that you do not have to insert a needle that often, making insulin intake less visible for the outside world and decreasing the influence of the disease on social life. The machine is relatively small, can be carried attached to the belt or in the trouser pocket — thus always available— and makes it possible to take in a well measured dose of insulin at exactly the right time. In real life however, children who use the machine are less well-regulated. It takes over the calculation part, but the input and planning — what did I eat, what will I eat, what will I be doing, and will it be strenuous or easy? — still has to be done by the patient. The pump allows for flexibility, letting go of the constructed regularity in eating and exercise, which makes a good regulation paradoxically more difficult. On top of all this, the introduction of the pump changes the target to which patients can comply, increasing the urge for perfection. As if control itself was not difficult enough.

5.2.4 Concluding; systemic reproduction

As stated in the introduction of section 5.2, following guiding question a), the number of patients with diabetes is increasing. Treatment is aimed at control via medical interventions, whereas the social world of the patient in which control has a different connotation, is just as important. The rising incidence of DM type II, which is seen as a life style related disease, makes care for the social part of the disease even more crucial. Dedding argues that for incorporation of the social, whether by incorporating tacit knowledge or by involving a patient in the decision making process, meaningful participation is vital. Participation is seen as a tool to improve both the quality and the acceptability of care, in terms of a good fit between care and the help
requested, as well as compliance to the therapy. Because of these positive
effects, participation is seen as contributing to the overall availability and
accessibility of care, because higher quality care is expected to lead to the
prevention of care costs later in the life of a chronically ill diabetic patient.
Therefore, patient participation has been an important policy goal for years,
but it appears that little progress has been made. By following and analysing
the reasoning and experiences of the intervention research as done by
Dedding, systemic reproduction of (care) problems can be seen in the ways
meaningful participation is impeded. This impediment does not imply that
Dedding’s intervention was unsuccessful, but the barriers Dedding had to
overcome made visible how the system manifests itself. Thus, these barriers
for meaningful participation still exist for most diabetic children.

The idea that diabetes is a controllable disease, because physical
knowledge and subsequent interventions exist, puts a tremendous pressure
on the practice. In the case of Dedding’s research intervention, the issue was
the agency of children and possibilities for them to define the disease in more
than just measurement numbers. The standardised application of this
measurement for control of DM pressures the professional to look for this
technical part of the treatment without leaving room for the child’s daily-life
problems. However, not only the health care professional is focussed on this
measurement, consumers of care, in this case children and their parents,
have also internalised the value of this measurement tool. When a
professional asks how things are going, a patient usually replies by presenting
the blood sugar values. In terms of controlling the disease, there appears to
exist a bias in solution pathways.

Patient participation demands a fundamental change in how patients
are perceived and in the space granted to the non-medical lay perspective in
formulating the problem definition and subsequent interventions. In the case
of diabetes care for children, as described and analysed by Dedding, health
care professionals do adhere to the analysis that meaningful participation may
improve care. However, they have problems implementing participation tools.
Setting up a shared problem definition is not part of their education.
Professionals thus reproduce in daily practice their role as medical expert. In
this medical system, the patient’s social environment plays only a limited role.
It is not that professionals do not acknowledge the social factors, but a focus
on the HbA1c levels instead of room for lay knowledge has been
institutionalised. Other actors that are not directly present in clinical practice
enforce these measurement tools, formalised in protocols. This is further
enhanced via technologies that draw on the discourse of hope, control, and
how new technologies can help to lead a care-free and active life. As such, the
reduction of health to a purely biomedical issue, and it subsequent negative
side effects, are reproduced here. These factors combined leave little room for
the children to function as co-producers of care. A possibly helpful reciprocal
relationship between practitioner and patient depends on the amount of room
both actors grant each other. In the current system, health care professionals are not granted sufficient room to grant their patients the room they need to participate in meaningful care. Even though Dedding successfully created space for some diabetic children and helped health care professionals to embed this in their daily work, a wider implementation of the patient as co-producer of care is problematic.

5.3 Interapy

Mental health care is organised for people with psychological problems. Most reported disorders are depression (20 per cent of patients), anxiety disorders (19.6 per cent), drug- and alcohol abuse (19 per cent) and behavioural problems in general (GGZ-Nederland, 2010b). Mental health care (GGZ: Geestelijke Gezondheidszorg) in the Netherlands aims for both prevention and treatment.80 One of the goals of treatment is to keep people active as members of society. This means preventing that people drop out of their work and life routine.81

The consequential costs of mental health problems are considerably higher than the direct costs of care. About one third of those unable to work have a psychological disorder. Also, about one third of sick leave is caused by pressure of work and stress. Furthermore, mental health problems decrease productivity. Depression and burn out, for instance, are characterised by lack of energy and concentration problems. The productivity loss of an employee with mental health problems is more than four times as high as that of an employee with physical health problems (GGZ-Nederland, 2010a).

Several challenges exist. First, there is an ever increasing care demand, putting pressure on general practitioners and RIAGGs (InformatieSteunPunt, 2003). In 2009, secondary mental health care had one million patients (GGZ-Nederland, 2010a). In total, 1,896,700 adults (eighteen per cent of the adult population) were registered with psychological complaints in 2009, leading to significant limitations in functioning. In the Netherlands, 43 per cent of the population had a psychological disorder at some point in their life. Of these people, 29 per cent used regular health care facilities. Secondary mental health care treated 21 per cent of this group. Ten years ago, this was only sixteen per cent (GGZ-Nederland, 2010a).

Related to this increase in care demand is the expectation that a too high percentage of the work force will have to work in mental health care in the near future (GGZ-Nederland, 2010b). This might add to the already

existing worry that patients too often have to wait too long before they receive treatment, making the health problems worse (InformatieSteunPunt, 2003).

Another challenge is the apparent entanglement of somatic and psychological complaints. It has been shown, for instance in the case of a heart attack, that depression heightens the chance of reoccurrence of somatic complaints. Furthermore, the combination of depression and diabetes negatively affects the prognosis considerably. Professionals in mental health care increasingly acknowledge the mutual influence between those historically separate fields, but how exactly they are interconnected is unknown. Currently, GGZ-Nederland provides and develops several different treatments for people with somatic complaints, but the care is still highly fragmented (GGZ-Nederland, 2010b).

Moreover, estimations are that about two-thirds of people with psychological complaints do not receive treatment at all. Possible reasons are that people want to solve the problems by themselves, believe the complaints might disappear without treatment, or do not know where to look for help. Another possible reason is the (increasing) length of waiting lists82 Complex financing structures make it harder to react to these challenges, according to professionals. Most notably, a barrier exists between the Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten; AWBZ) and the health insurance act (Zorgverzekeringswet; Zvw). Two completely separate systems for financing and controlling exist, which makes life difficult for patients and burdens the institutions with more administration (GGZ-Nederland, 2010a).

Interapy is a new practice that developed psychotherapy through the Internet by combining new technological possibilities with traditional psychotherapeutic treatment. This approach has, according to the initiators, several advantages: first, treatment can commence almost immediately after informed consent of the patient; second, treatment is available when and where patients find it feasible; third, the patient has more control over treatment as a whole; fourth, the program and time-span are easy to oversee; and last, Interapy designs and implements instruments for patients to stay healthy.

The practice is not explicitly set up to improve health care in a broader sense, or to overcome identified problems — even though its approach seems to fit the problems prevalent in the sector. The first section of the analysis therefore is not designated ‘solutions for what care-problem’, but ‘perceived possibilities for improving care’. Interestingly, exactly the advantages of this new treatment appear to conflict with current health care arrangements, even though Interapy treatment is based on commonly used face-to-face behavioural therapy, and shows comparable outcomes. The success and

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impact of Interapy are impeded by, for instance, expectations of health care professionals and patients, financial, planning and other rules, and compartmentalisation of the health care system.

5.3.1 The practice; perceived possibilities for improving care

The description of the new practice and analysis in subsequent sections is based on, and takes as its starting point, the work of Erica ter Haar and a set of conversations with her in which we discussed both her and my analyses. Relevant issues were further investigated by making use of literature from several scientific backgrounds, such as the social and biomedical sciences. Ter Haar did a series of interviews with the initiators of the new practice Interapy and with actors relevant for the functioning of this practice. Ter Haar's goal was to investigate in what ways power played a role in the support and impediment of this novel health care intervention. This section re-analyses her work through the lens of systemic reproduction of health care problems by applying the quick scan version of the method developed in chapter two, of which question a) is answered above, and question b) is answered in this section.

The company Interapy provides a treatment developed by the department of Clinical Psychology and the department of Social Science Informatics of the University of Amsterdam. It was one of the first psychological treatments via the Internet, eliminating face-to-face contact between professional and patient. The idea of Interapy treatment arose from an informal meeting between a professor of Clinical Psychology and an Internet-expert. A research project was started in 1997.

In 2001, the independent treatment organisation Interapy was set up, and began with providing treatments for diseases with a high incidence (like post-traumatic stress syndrome, burn-out, and depression) to ensure a large target group. Interapy developed, up to 2008, treatments for short-term psychological care programs for people with post-traumatic stress syndrome (PTSS), mourning complaints, work related stress, depression, and panic complaints, and provided help to adolescents after sexual harassment. To evaluate the efficacy, every new treatment was set up as a research program. Clients could participate for free as part of the study. When the effect was sufficiently proven, a treatment protocol was defined to create an official (and no longer free) Interapy treatment. Interapy thus focuses on providing only evidence-based treatments.

All Interapy treatments have a fixed goal and a known average duration. Before treatment can commence, an online questionnaire is filled

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83 A version of this analysis with a slightly different focus will 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).
out to determine if the treatment is suitable. Patients with suicidal behaviour, or psychoses, or serious dissociative identity disorder are excluded. After an informed consent form is signed, treatment commences. The basic format laid down in protocols is: the client makes an assignment and the therapist reacts to the client’s contribution, leading to instructions for the next step. On average there are two contact moments in a week, which is why the duration of the total treatment is shorter than in face-to-face therapy. The average duration of Interapy treatment varies by treated complaints, from eight weeks for mourning complaints to 21 weeks for the treatment of depression. The client communicates with his or her therapist via a secured website. All information exchanged is preserved, so the client can reread it if desired. Ex-clients say these personal development tools are helpful in maintaining healthy behaviour.

The results are measured by automatic screening before the treatment, immediately after the treatment, six weeks later, and a year later. Of all clients, eighty per cent show a significant improvement after treatment and sixty two per cent are free of complaints a year later. The results are comparable with qualitative face-to-face cognitive behavioural therapy, based on a series of studies conducted in cooperation with the University of Amsterdam. In addition, research carried out by the Trimbos Institute shows Interapy is clinically, as well as economically, effective (Riper et al., 2007).

The perceived possibilities for improving care are reflected in the characteristics of Interapy care as developed over the years: high accessibility (the treatment commences directly after informed consent), treatment at a time and location convenient to the client, client responsibility for the treatment, a relation of trust without seeing the therapist, decreased shame, the possibility to deal with emotions in the client’s safe environment (i.e. at home behind one’s computer), a transparent program, and development of personalised instruments for staying healthy. Through these features, Interapy also offers opportunities for early intervention and prevention, preventing patients from dropping out of social and working life, as well as relapse.

On an organisational level, in the course of the development of Interapy, the novel practice eventually became embedded in existing mental health care. First of all, Interapy treatment was bought in by the employability services of several large companies, for example, an airline company, to provide treatment of occupation related disorders, like burn-out and PTSS. The advantages of Interapy are recognised by these companies partly as a result of changes in the law\textsuperscript{84} that made employers (financially) responsible for the health of their employees. These changes encouraged a move from responsibility for safety on the job towards improving employability and reintegration of employees. Here Interapy thus functioned

\textsuperscript{84} Work capacity act: WIA: wet Werk en Inkomen naar Arbeidsvermogen.
autonomously from the regular health care system, providing prevention and reintegration services bought by companies. This also meant that regular treatment pathways via the general practitioner, which usually take longer to commence, were circumvented.

This kind of (medically unacknowledged) care was however not what Interapy considered its contribution to the care system should be. Besides, the novel practice needed more financial stability. For those reasons Interapy sought new opportunities. One important option was to become a regular therapy general practitioners could refer to. To make this possible, Interapy had to become acknowledged as an exceptional medical expenses act (AWBZ: Algemene Wet Bijzondere Ziektekosten) institute. For this, Interapy had to prove to the Health Care Insurance Board (College voor Zorgverzekeringen; CVZ) committee that it was able to treat complex psychological problems. At first, positive results from several researches were ignored by the committee, primarily because some members felt that if treatment via the Internet was possible, the psychological disorder could not be that serious. After several procedures, including effect research, expert advice, and the threat of a lawsuit, Interapy acquired an AWBZ permit in 2004. This meant that Interapy could function as a traditional mental health institute. In 2007, all secondary psychological help, including Interapy, was transferred from the AWBZ to the health insurance act (Zvw: zorgverzekeringswet), aligning it with primary psychological care. Since January 2008, all acknowledged psychological care falls under the health insurance act, and Interapy treatment became available under the basic reimbursement rules.

In the end, Interapy scaled up and diffused its treatment by making it part of regular treatment structures. One of the ways in which this was done was by training other professionals working in regular mental health institutes. Institute A is a mental health institute in a rural area. Because of the large service area and infrequent public transport services, Interapy as treatment via the Internet fitted the goal of decentralising care towards people’s own homes. Around 30 professionals were trained and, in cooperation with Interapy, the instrument ‘I-check’ for early intervention was developed. Interapy treatment was however not easily accepted by professionals, as further investigated in section 5.3.4.

The implementation of Internet-based treatment initially went more smoothly in Institute B, where 12 therapists were trained. The institute focuses on EBM-treatment, and the positive outcomes of the effect research of Interapy was convincing for these professionals. Although the practitioners promoted Interapy by emphasising, first, the value of an almost instant beginning of therapy, circumventing the existing waiting lists at the institute, and second, the possibility of following treatment at the client’s own place and time, most clients refused the offer. They felt they were turned down for regular treatment, and being offered an unfavourable alternative. Particularly those clients who had self-registered expected face-to-face therapy. Institute
B managed to treat 100 clients in the first year, but because it remained difficult to convince clients that this therapy might be helpful, they stopped offering Interapy treatment.

In 2008, the Interapy organisation was purchased by six mental health care institutes; Interapy has become fully institutionalised in the traditional arrangement.

5.3.2 The practice; premise and expectations

As stated, Interapy did not depart from an articulated care problem, but saw possibilities for improving quality of care by making use of more general developments and combining them with existing features of mental health care. Interapy drew on the new regime element of people using all kinds of services provided through the Internet that came into being as part of the information society. Concurrently, in psychotherapy, treatment methods were introduced that use written assignments, a format which lends itself to Internet use.

An important feature of the new treatment perceived by Interapy as an improvement, was accessibility, signified, first, by the possibility of following treatment unbounded by time or place. This advantage was acknowledged by an airline company. The employees could now follow therapy regardless of the location and time-zone they were in. The employability services of the airline referred an average of one or two employees a month to Interapy. The second improvement in accessibility was reached by making use of a quick intake procedure, after which treatment could commence almost instantly. Interapy offers a quick scan to determine if an employee has post-traumatic stress disorder. Here, Interapy reacted to how they perceived the regular institutionalised route, which goes via the company doctor, general practitioner, and finally a mental health care institute, and usually starts only after the employee stays home from work. Both improvements were indeed perceived as appealing by companies, because Interapy treatment can be applied while the employee is still working, thus preventing drop-out.

Another important issue in the development of Interapy is face-to-face therapy. Interapy is based on the assumption that psychotherapy via the Internet is at least as effective, complemented by the advantages mentioned above. The focus was therefore on proving that their treatment is comparable with face-to-face treatment, structuring their research protocols. Here the professional value of Interapy manifests itself.

The assumption was that changing face-to-face therapy, where the professional sets the agenda, into a patient-driven assignment-based therapy, would also lead to an improved position of the patient, giving the feeling or greater control than in regular treatment. While no face-to-face contact is made, professionals working at Interapy find it important to provide
personalised care, adjusted to the context of the specific client. A necessary condition for this is a reliable and personal relationship between professional and client. Interapy believes this can be done through the Internet as well, as long as their EBM-proven protocols are followed.

As described, Interapy started to search over the course of the development for other reimbursement structures, partly because the contracts with several companies did not bring financial security, and partly because Interapy’s ambitions were in health care, not in providing non-medical preventive measures, which would require, and yield, new alliances outside traditional health services. Obtaining an AWBZ permit became the goal, based on the expectation that more patients would be attracted if Interapy would be an official mental health care institute in which treatment is reimbursed. Reimbursement of therapies by the AWBZ depends, logically, on whether the particular institute itself is acknowledged as providing the kind of care described in the AWBZ. Interapy therefore focused on psychotherapy instead of, for instance, prevention courses.

The choice of Interapy is also rooted in the desired professional identity. Besides the financial reason, Interapy’s (unspoken) value is that providing treatment has a higher professional status than coaching or training, a value shared with most professional health care institutes. This professional identity, based on providing EBM-proven interventions from within acknowledged and sanctioned medical institutions is then symbolic capital, which Interapy acknowledges and reproduces.

In general, the financial director of Interapy was convinced of the (positive) effects of the treatment, and did not understand why Interapy treatment did not diffuse faster.

5.3.3 The practice; support and impediment

Interapy has some promising advantages in terms of the possibility of coaching the patient in becoming a co-producer of care. Interapy offers flexibility and control to patients, while making them responsible for their own healing process. How this was done, however, did not easily fit in with existing structures. Interapy is not explicitly set up to solve problems in health care, but aims to improve care for a specific group of patients. When clients have followed Interapy treatment, most of them are positive and see its benefits over regular face-to-face therapy. Those clients experience more independence, as well as more responsibility for their own treatment, in comparison to traditional therapy they have been following. Although the Interapy treatment follows a protocol, the client is mostly in control of the planning process itself. The therapist then reacts within 48 hours to the client’s contribution. In this setup, the practice departs from the problem definition of these patients. This, inconveniently, required a new institutional arrangement, whereas Interapy wanted to be part of existing arrangements.
This led to several clashes, even though the features of Interapy could improve the quality of care.

First of all, it appeared, according to Interapy, that general practitioners did not easily refer patients that were eligible for the new treatment to Interapy. Three reasons for difficulties for general practitioners to change their referral behaviour were mentioned. First, for professionals it is hard to believe that a therapy in which clients are not seen will work. Furthermore, medical practitioners work according to a tight schedule. Since Interapy does not adhere to this, practitioners are afraid Interapy will not monitor the progress sufficiently. Last, practitioners usually refer to other professionals they already know. Interapy thus had problems attracting patients before they became an AWBZ-acknowledged institute.

Becoming an AWBZ-acknowledged institute, however, had a perverse effect. By making use of the shift in responsibility for the health of employees to employers as laid down in work capacity act, Interapy at first stepped into a market of offering preventive measures to companies. The advantage of Interapy offering quick access and tools for prevention of sick leave are recognised by the mentioned companies. So before Interapy got an AWBZ permit, the companies themselves paid for the treatment, arguing that if sick leave is shortened by one week, the treatment would have paid itself. However, Interapy wanted to obtain an AWBZ-permit, and with its acquisition in 2004, Interapy became part of regular Dutch health services. From that moment on, employability services needed a doctor’s referral for Interapy treatment, because employers did not want to pay for treatments eligible for public reimbursement. Getting a referral, however, can take weeks, meaning the advantage of quick access to treatment was lost. The focus on care of the AWBZ, also propagated by Interapy, undid the preventive potential of the new Interapy treatment.

In the process of getting the permit itself a set of legal structures impeded Interapy. Before starting a procedure at the CVZ to get the AWBZ permit, Interapy decided to request an audit from the inspection of public health. This audit was meant to judge if Interapy remained within the existing legal framework. Interapy also figured that taking this unusual action — the inspection commonly does not audit institutions at the request of the institution itself, but when quality issues arise that demand an inspection — might help to get the AWBZ permit. The inspection’s verdict was positive. One point of critique was that Interapy did not employ professionals registered under quality of professionals act (Wet-BIG: *Wet op de individuele Beroepen in de Gezondheidszorg*). Interapy argued that although they used basic (unregistered) psychologists, quality was safeguarded by the used protocols, specialised training, and supervision. This was problematic, because the law describes quality rules for professionals, not for protocols or methods.

Surprisingly, the positive outcome of the audit was not followed by a smooth AWBZ permit procedure. A more severe obstacle proved to be the
position of the psychological experts at the CVZ when they expressed a lack of confidence in treatment of psychological problems without meeting the client. Embedded in the general dispositional structures was the idea that the unique healing relationship cannot be built with written therapy, and without face-to-face contact. This was something the positive evaluations, also of for instance the Trimbos institute (Riper et al., 2007), could not change.

This perception on what facilitates high quality care was also encountered by health care professionals and by (possible) patients. In Institute A, there was much aversion to Interapy treatment coming from the health care professionals working there. According to the director of Institute A, this could be attributed to the idea that the unique healing relationship cannot be replaced by Internet. Interestingly, this did not originally appear to be a problem when Interapy treatment was bought in by an ICT company. Interapy and the health service of the company expected that this group of patients, comfortable about working with Internet-related services, would accept Interapy as a favourable alternative to face-to-face therapy. Treatment was aimed at employees with burn-out and followed the regular protocol-led treatment in which the therapist modified and adapted the standard to the personal situation of the client. It turned out that the employees feared they were receiving automatically generated answers and doubted an actual therapist was responding to their assignment. This prevented the vital trustful relationship of patient and professional.

Thus, in both Institute A and an ICT company, the coupling between a healing trustful relation and face-to-face therapy plays a profound role. An important barrier mentioned in relation to all institutes with which Interapy had partnerships, is that this general-dispositional structure of psychological professionals as well as patients is hard to change. There are differences, however, to the robustness of this barrier, which appear to be related to the age of the professional. Older professionals are in general educated by the psychodynamic school of thought, whereas younger professionals are also trained based on the ideas underlying psychotherapy. In general, the professionals that have been trained when psychotherapy was an acknowledged field in psychology are more open to Interapy — which can be seen as digitalised psychotherapy.

In Institute B, another unexpected issue arose. The patients who refused treatment were unimpressed by the alleged advantage of Interapy treatment of giving the patient the idea that he or she was personally in charge. These patients explicitly sought professional help to solve their problems. Related to this, the change in relation between professional and client, in which the client is actively involved in setting the problem definition, did not appeal to them.

According to Ter Haar’s analysis, several other forms of institutional resistance were relevant during the process of integrating Interapy treatment in regular care arrangements. Professionals were not always motivated to
provide Interapy treatment in their company after training. But if they were, external structures of the arrangement in which they functioned suddenly turned out to be impeding, like planning rules\(^{85}\) and referral problems\(^{86}\). The flexibility in time and place functions well in the Interapy organisation, but planning-problems occur in traditional health care institutes when a client has not delivered their contribution at the planned moment. Planning and registration structures in the traditional arrangements and habits in how work should be done are not equipped to deal with clients who control the time schedule themselves.

According to Ter Haar, those barriers can be decreased when the Interapy training is taken seriously, and Interapy treatment is part of a wider mission of enlarging accessibility of care within a company. Because of these barriers in the external structures of Interapy, the expectations about Interapy of the involved project leader in the institute are important. At the majority of mental health care institutes, Interapy treatment stayed a marginal part of the treatment programme, and some stopped the new treatment altogether.

Interestingly, some clients have the same hesitations as professionals, based on expectations formed by traditional health practices. In one mental health institute, clients on the waiting list were invited to take Interapy treatment instead of face-to-face psychotherapy. Most of them refused the offer and rather waited for regular therapy. They had the feeling of being turned down and offered an unfavourable alternative.

### 5.3.4 Concluding; systemic reproduction

As stated in the introduction of section 5.3, following guiding question a), the number of patients in mental health care is increasing. Not only does this lead to direct care costs, but also to secondary costs since patients can drop out of their work routine. Furthermore, bad mental health has even more negative side effects if somatic and psychological complaints are intertwined. About one third of sick leave in general may be caused by pressure of work and stress. Especially for this group of patients, Interapy might have added value. Barriers for seeking help before it is too late are lack of time, scheduling problems, or shame. Interapy overcomes these barriers and thus promises to offer a combined solution to improve quality, acceptability, availability, and accessibility of care. The most prominent element of this care is the improved control of the care process for the patient. Furthermore, the high accessibility helps to coach patients while they continue to work, thus preventing further

\(^{85}\) Interapy is just a small part of total treatment; most is planned, which lowers flexibility. It could be that the client did not react at the agreed time. Furthermore, two contacts versus one a week is against the ‘normal’ treatment rhythm.

\(^{86}\) Because of professionals who are simply unaware of Interapy, while being at a key position in the organisation.
damage. The approach has the promise to improve the possibilities for the patient as co-producer of care.

In the analysis of the novel practice above, a couple of recurrent issues are visible. First, improved accessibility (as perceived by Interapy, and recognised by other professionals, companies, and patients); second, the need (for Interapy) to stay financially healthy; third, the professional value of the focus on treatment instead of on preventive tools (Interapy and other professionals); and last, the professional value that treatment cannot be done without face-to-face contact (other professionals, health care policy workers, and patients). This is related to a focus on treatment being evidence-based.

Searching for funding steered the behaviour of Interapy, but it does not fully explain the choices made. The professional value of focus on treatment was of vital importance. Interapy therapists have the same profession and basic education as other mental health care professionals. Therefore, their general dispositional internal structures contain professional values that are consistent with other agents in the traditional arrangement: treatment instead of giving advice or coaching, the importance of the relationship between professional and client, and the effect of the treatment are important. This is reflected in how Interapy steered itself into becoming a regular mental health care institute, in interaction with the admission criteria of the AWBZ, and thus missing the business opportunity of offering preventive courses. A health service worker of a company who uses Interapy treatment in occupational health stated: ‘Maybe Interapy could have more business if they focused on prevention in training courses, instead of focusing on treatment. Managers are willing to pay if workers are treated in a way that they can keep on working, or in a way that they return to the work process faster.’ The growing number of people declared fully disabled has become a great burden to the welfare system over the last decades. The Dutch government has reacted by implementing changes in the disability act (Wet op de arbeidsongeschiktheidsverzekering; WAO), making employers more (financially) responsible for the health of their employees via the work capacity act (wet Werk en Inkomen naar Arbeidsvermogen; WIA). These changes encouraged a move from responsibility for safety on the job, towards improving employability and reintegration of employees. One of the aims was to stimulate employers to take preventive measures, to which Interapy reacted. But Interapy’s focus on treatment undid this potential improvement.

Much to the surprise of Interapy, another 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 did not want this freedom, but wanted designated professionals to help them. The idea of more personal responsibility for one’s health, based on the propagated practice of written assignments, collided with the health seeking behaviour of this group, who expected personal care and a health care professional 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: reactive without focus on prevention. Staying healthy is therefore not rewarded. This helps the reproduction of the idea that a patient is not responsible for one's own health.

Furthermore, the initiators of Interapy emphasise the importance that all psychological treatment must be evidence-based; they thus make the effort to base all treatment protocols of Interapy on scientific evidence showing the treatment's effectiveness. Internet therapy fits the characteristics required by the methodology underlying evidence-based medicine. First of all, all interventions (in terms of assignments or feedback given by practitioners) are written and saved and thus available for extended analysis. Second, it is easy to incorporate electronic questionnaires, meant to evaluate Interapy, into the treatment. Related to that, Interapy chooses to treat one disorder at the time, because this is the only way to measure treatment results. Rules of scientific effect research thus influence treatment and treatment options.

The possibilities of Interapy to improve care appear to be impeded by patients and health care professionals in existing institutions, who reproduce existing structures. But Interapy itself also reproduces features: the focus on more specialised care undid the advantages Interapy could have in providing preventive treatment, overcoming the borders between the occupational and the health domain.

5.4 Quick scan and reproduction of problems

This chapter had three goals, of which the first was to investigate whether structuring features and care issues that seem prominent in the case of patients with MUPS are also relevant in differently situated practices. The two cases analysed in this chapter added to the existing analysis of features and mechanisms that underlie the reproduction of enduring problems. The second goal of this chapter was to show the method can be used as a (policy) tool to investigate, for instance, optimisation problems in health care. For this purpose, third, the UPP framework was further specified. In this conclusion, I work back from goal three to goal one.

The UPP framework 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. If a new set of interviews with relevant actors is necessary to complete the analysis, then the whole idea of a quick scan is undone. Interestingly, the complete dissertation of Dedding lent itself better for the quick scan than the one chapter 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 as
secondary researcher to make a better connection between systemic features
and how they play out in practice. This leads me to believe that a good
iterative analysis of systemic reproduction should incorporate both interviews
and observational analyses, as I did in the MUPS case.

This is not to say that the quick scans performed in this chapter did
not deliver interesting insights; they do, which I will elaborate below. More
importantly however, the further specification of the method makes it possible
to leave out the ‘heavy exercise’ of a full historically informed system analysis
as I performed in chapter three. By looking into a set of policy documents and
in iteration with reading about the practice in focus, it still appears possible to
investigate why it is so difficult to optimise health care practices. Without
connecting to deeply embedded systemic features, it is still possible to
unravel relevant systemic features. This information can be used to help
practices overcome those barriers. From a policy perspective, this can be used
to optimise health care. And because the analysis stays closer to the case,
both in a temporal dimension and in philosophical abstraction, actions for
change are easier to implement.

These analyses themselves can be used in iteration with the earlier
system analysis. What seemed relevant in the MUPS case was how the novel
practice, implicitly, worked on making the patient a co-producer of care. This
notion however only surfaced because of the analysis of the diabetes case, in
which the creation of the possibility of patients to actually become co-
producers was central. And even though not explicitly, this also appears to be
an important notion in the Interapy case. Ultimately, this notion of the patient
as co-producer of care might be a solution to a series of care problems, which
is impeded by how negative side effects of success factors are reproduced.

In previous chapters, a small set of relevant success factors were
listed based on an iterative analysis. Furthermore, the mechanisms of
reproduction were described. For both practices analysed in this chapter, all
the four factors (standardisation, protoprofessionalisation, specialisation, and
evidence-based medicine) are relevant. In the diabetes case, these factors
have contributed greatly to the care for patients. Whereas diabetes used to be
lethal, it is now a chronic disease, though with severe possible complication.
In this disease, life style related factors are very important. As it turns out,
these life style related factors are difficult to fit in, or be controlled by, the
standardised and specialised care professionals have to offer.

In treatment for the disease, 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. In the case of care for patients with MUPS, protoprofessionalisation
played an almost decisive role. In the case of diabetes care for children, at
first the opposite seems to be true, in the sense that the children do not want
to be part of the medical discourse and they formulate their problems in social terms. On the other hand, the parents do appear to focus on medical interventions to help the children stay healthy, supported further by the optimistic message of new technological developments. And although the children fight the prominent place of the medical discourse, they are extensively trained in and disciplined by the medical side of the therapeutic plot. One could say that the children, although they are younger and therefore not as socialised in the medical discourse, still perform it. Ultimately, their voice is weakened by the protocolled diabetes care that favours medical scientific knowledge. The specialisation in care further diminishes the possibilities of room for lay knowledge, of which the Diabetes Control and Complications Trial is the institutionalised version. All of these issues are further strengthened by the institutionally embedded evidence-based treatment options that dictate what treatment is reimbursed. For meaningful participation, those success factors are impeding factors.

An interesting new insight that the diabetes case delivered was how the supply side draws on these features and on the discourse of control, thereby contributing to the existing barriers. In the MUPS case the supply side is present, but not as prevalent. Even though one could say that companies that sell full body scans are on the same level.

In the case of Interapy, the same kind of systemic reproduction comes to the fore as in chapter four: the initiators have a focus on scientifically validated, medical professional interventions that are acknowledge as such by the institutions, thereby overlooking possibilities. In the case of Interapy, the opportunity is to fulfil a much appreciated role as preventive care provider for corporations. Underlying the 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. Because health care is divided in many 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. This systemic feature manifests itself in both the internal structures of the CVZ and the professionals of Interapy. This, also financially embedded, professional value drove Interapy towards treatment and health care, instead of towards work-related prevention courses.

Furthermore, the institutionalised version of standardised health care practices directly opposed the added value of the flexibility that Interapy offered. Professionals that were eager to implement new Interapy treatment into their own organisations were impeded by those existing structures. Here too protoprofessionalisation played a role, because a set of patients, first, did not think this new treatment was real because no face-to-face contact exists, and second, that a more active personal involvement is not what a medical system should offer. A medical system based on medical knowledge should provide medical care, not ask for non-medical self-administered treatment.
Even though Interapy had internalised the value of treatments being evidence-based, both for them and as acknowledgement of the systemic value of EBM, this in itself did not appear to pose any problems. Even though their treatment is just as personalised as the treatment in the MUPS case and the patient population is just as heterogeneous, there appeared to be less methodological problems. This may indicate that the very successful set of evidence based practice travels and is translated to fit the setting in which it is applied. This, however, does not help the initiators of the clinic for unexplained diseases because their setting still is an academic hospital and not a mental health institute.

In conclusion, one can say that both practices described in this chapter have the aim to improve quality, acceptability, availability, and accessibility of care. And both have the promise that in doing so they contribute to a solution for the tenability problems of the Dutch health care system. Central in the approaches is a shift on the axes cure-care and mind-body, like in chapter four. Furthermore, both practices are looking for new configurations, in which the patient has a more prominent role. Not only in terms of compliance to therapy, but in co-defining the problem and subsequent interventions. After analysing those practices, one can say that the patient as co-producer of care may be an answer to enduring problems in health care, but implementation of this principle is impeded by existing structures.