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Embodied Interventions— Interventions on Bodies: Experiments in Practices of Science and Technology Studies and Hemophilia Care

Teun Zuiderent-Jerak[1]

Abstract
Science and technology studies (STS) analyses of emerging forms of treatment often result in the detailed display of complexities and at times lead to explicit critiques of particular healthcare practices. Simultaneously, there seems to be an increasing interest in exploring more experimental engagements by STS researchers in the proactive construction of such practices. In this article, I explore the relevance of experimental interventions in health care practices for both these care practices and for issues of the normativity of STS research. By analyzing my involvement in changes in the practice of hemophilia home treatment, I indicate how this care practice was

[1] Erasmus University Rotterdam

Corresponding Author:
Teun Zuiderent-Jerak, Institute of Health Policy and Management, Erasmus University Rotterdam, P.O. Box 1783, 3000 DR Rotterdam, Netherlands
Email: zuiderent@bmg.eur.nl

reconfigured, partly by drawing on STS insights on the issue of compliance. I also claim that experimenting with forms of "artful contamination" allow STS researchers to *do normativity* in the practices they engage with. Such practices of interventionist STS research may be of value for refiguring debates in which constructivism has been accused of being normatively deficient. This may make interventionist STS research a fruitfully risky business.

> Many older hemophiliacs look back on childhood years of missed opportunities which have resulted in poor quality jobs and long periods of unemployment. The reasons for this are not difficult to find. Effective treatment with concentrated blood products has not been available for long, and children used to be put to bed for weeks of rest after bleeds (. . .). Nowadays the outlook for even the most severely affected hemophiliac coming up to school age has never been brighter. The child who is intellectually capable of going on to higher education should have as much chance as an unaffected child of doing so. (Jones 1984, 153).

Solutions and Their Problems

This quote by one of the "founding fathers" of modern hemophilia treatment is typical for popular accounts of the impact of technological developments in medicine on the lives of patients. As is the case for many chronic diseases, the story about the development of hemophilia treatment is replete with the rhetoric of progress. And this is somewhat unsurprising: as in many other cases, the opportunities for patients to participate in activities from which they would previously have been excluded have improved immensely. In addition, their life expectancy has increased and they face fewer problems with damaged joints due to bleeds.

Although the advances in medical treatment of chronic diseases seem obvious, seeing them as mere improvements in an otherwise static environment is not unproblematic. As authors from the field of science and technology studies (STS) have observed when researching the development of medical treatment, new forms of care or the introduction of new medical devices often produce new issues in the sociotechnical interplay of patients, doctors, devices, and institutions.[1] From this theoretical perspective, developments in care for (chronic) patients can be seen as *alterations* rather than mere

solutions. This then leads to sensitivity for the issues that newly defined "patients" and "care providers" must face in their transformed care setting.

Analyzing new forms of treatment and their consequences has been a primary aim for scientific fields like medical sociology and, more recently, STS. This analytical work has led to detailed studies of the complexities that such developments entail for patients and care providers. It has also, at times, led to critiques of existing care practices and to suggestions for addressing the problems that were analyzed. However, it has less often resulted in research practices where STS researchers get directly involved in the design and development of these care practices. In this article, I will explore some of the practical and conceptual issues that occur when STS researchers engage themselves with the *proactive construction of health care practices*. By bringing together STS insights and interventionist research, I hope to show how a particular practice—in this case hemophilia care—can be productively reconfigured through entangling it with STS insights and that such entanglements are consequential for debates on the normativity of STS research.

To achieve this aim, I first describe the emergence of "interventionist" approaches on the STS research agenda and the different ways "intervention" is conceptualized. I then turn to a research project, for which I was actively involved in the construction of a hemophilia care center (HCC) of a Dutch University Hospital, and unpack what the consequences were of my involvement in this organizational change project. Finally, I discuss how the insights from this project may be relevant for the normativity of STS research. I propose that a situated normative approach is emerging that allows for a reply to the critique that constructivism would be "normatively deficient," without turning toward prespecified normative agendas (of, for example, social movements), as proposed by authors who have been referred to as "critical STS" (Hess 1997).

STS Research and Intervention

The history of discussing practices of STS research as "interventionist" is far from recent. One of the important contributions to this debate is the series of publications exploring the notion of the "capturing" of STS researchers by one side of a controversy (Collins 1990; Scott, Richards, and Martin 1990; Martin, Richards, and Scott 1991; Blume 2000). Capturing refers to the situation where studying a controversy symmetrically, that is, using "the same types of cause [to] explain, say, true and false beliefs" (Bloor 1976)[2] is bound to produce an account which is alternative to the one

that draws upon established notions of truth and falsehood. As Steve Woolgar already noted prior to these publications, such an ''alternative account will be heard as a comment on the adequacy of the original account'' (Woolgar 1983),[3] and therefore ''the party with the lower credibility may seize a neutral account because it implicitly levels the playing field'' (Hess 1997, 161). A major contribution of these publications is that they make it compellingly clear that maintaining a ''neutral'' position is simply impossible in the study of controversial practices of technoscience. However, this does not equal saying that ''taking sides'' is inevitable[4] and that STS researchers should therefore ''get real'' about whose side they are on. Rather, the point is that there will always be an interesting interplay between the positioning of STS researchers and the field they try to engage with.[5]

The notion of ''capturing'' was developed in relation to the study of scientific controversies and, perhaps as an artifact thereof, has been conceptualized as the aim of one homogenized ''party''—the underdog—to capture the STS researcher. However, as Brian Martin later pointed out, there may be many cases in which the STS researcher can be seen as both *captured* and *capturing*. Therefore, ''the term 'capture' is perhaps the wrong word since it connotes unwillingness on the part of the captured. 'Mutual enrolment' or 'joining forces' are more appropriate descriptions'' (Martin 1996, 265). Such willingness of the STS researcher to become part of the controversy under study is further explored by Martin in terms of what he calls ''partisan intervention'' and ''open partisanship'' (ibid). He investigates these notions on the basis of his fascinating involvement in the scientific controversy over the origin of AIDS with the aim ''not to argue for intervention as an inherently superior approach (. . .) [but] to say that it should be recognized as an approach that is useful for certain purposes'' (Martin, 1996, 267). Martin introduces three conceptualizations of ''intervention,'' being, first a sliding scale from ''complete observation at one extreme and complete participation at the other'' (ibid, 262), which he calls the ''usual'' conceptualization. The second is a sliding scale of unobtrusive observation and, what Harry Collins called, ''participant comprehension'' (Collins 1984; and which Collins later conceptualized as ''interactional expertise'' [Collins 2004; Giles 2006]) which means that ''the social scientist learns about the area by trying, however temporarily, to pass as a competent member or native'' (Martin 1996, 262). The third scale Martin introduces focuses on the intentions and the purpose of research and conceptualizes intervention as the extremes of aiming at ''nondisturbance and major change'' (ibid). According to Martin, the first two notions of ''intervention'' have been developed by researchers whose primary goal was understanding practices through

partisanship. His own purpose "by contrast, was at least as much to effect change as to gain understanding" (ibid, 263), which leads him to this third conceptualization.

The development of STS researchers conceptualizing intervention as aiming to change practices is historically and theoretically situated by Gary Downey and Joseph Dumit (Downey and Dumit 1997a,b; Downey and Lucena 1997) and by David Hess (Hess 1997, 2001). Downey and Dumit relate their notion of intervention to the "transition taking place in critical intellectual work, from opposing or praising technoscientific practices to intervention, from necessary entrenchment to ongoing participation" (Downey and Dumit 1997a,b, 10). Here, intervention is no longer situated in the ethnographic figuration of practices but in "forms of critical partic-ipation" (ibid). They situate the shift from critique and opposition to inter-vention and participation as part of "a fundamental change taking place in the academy itself" (ibid).[6] When exploring interventionist practices of "hiring in," indicating the willingness of STS researchers to "allow their work to be assessed and evaluated in the theoretical terms current in the field of analysis and intervention" (1997, 119), Gary Downey and Juan Lucena make a case for broadening the repertoire of social scientists to "encourage the growth of collaborative relations in academic work and relocate the agonistic politics of rebuttal from a necessity to an option in the everyday practices of academic researchers" (ibid, 120).

David Hess situates the turn toward intervention in long-term debates about where and how the normativity of STS researchers should be articu-lated. Drawing upon Martin's claim that STS has depoliticized its "roots in activist struggles" (Martin 1993)[7] and its base in "radical social move-ments: radical science, feminism, women's health, civil rights, environmen-tal justice, peace and so on" (Hess 1997, 157), Hess links the emergence of interventionist approaches to critiques that constructivist studies provide "no grounds for making a decision about what course of action one ought to take" (Hess 2001, 236). He thereby voices a concern that has become pertinent in much STS literature: the challenge of how to avoid that con-structivism, through its meticulous deconstruction of facts and practices, produces nothing but ruins (Latour 2004). Hess suggests that there is a "sec-ond generation" of ethnographically inspired STS researchers who tend "to be more oriented toward social problems (environmental, class, race, sex, sexuality and colonial)" (Hess 2001, 236). This move provides such researchers with the normative base to "develop ways of intervening in their field sites as citizen-researchers and [to make] (. . .) their competence applicable to policy problems" (ibid, 239). In this sense, Hess views

interventionist STS as a combination of a sensitivity for social activism and movements and the analysis of the "way [practices] might be *better* constructed, with the criteria of 'better' defined explicitly and their contestability openly acknowledged as both epistemological and political" (Hess 2001, 240, italics in the original). Hereby, Hess follows a similar line of reasoning regarding the normative purchase of STS research as critics of—among others—Actor-Network Theory who refer to "the normative deficit of STS" (Keulartz et al. 2004, 12). For Hess, the normativity of STS research is relocated in the reconnection to its activist roots.

The ties between intervention and activism are further strengthened in a proposal for a "*rapprochement* (. . .) between the more academic and the more activist wings of STS" (Woodhouse et al. 2002, 297, italics in the original). When reflecting on the high value many—what the authors call—"reconstructivist" STS researchers ascribe to explicitly normative components of research, they define this normativity as: "scholars' relatively deliberate efforts to structure inquiry, description, and explanation to serve social purposes" (ibid, 298). With the definition of "reconstructivism" as the: "intention of conducting forefront scholarship aimed in part at helping to inform and deepen public enquiries, deliberations and negotiations concerning the democratic shaping and reshaping of technologies" (ibid, 299), they connect their focus on intervention to grassroots issues and the democratization of the design of technologies.[8]

The conceptualization of interventionist STS research as connected to issues of the proclaimed normative deficit of STS is certainly an interesting one. There are, however, reasons to believe that intervention and normativity can be brought together *without* linking them to activism, social movements, and the democratization of technology. Besides a substantial volume of work that connects intervention to social movements and democratization,[9] there is also a growing body of literature that unpacks how STS research intervenes in practices and is normatively relevant without connecting it to participatory or activist democratic models.[10] It is to this body of literature that this article wishes to contribute.

I propose that though *both groups* of researchers exploring the notion of intervention "intervene" in the issue of the "democratic deficit" of STS, the conceptualization of intervention as proposed by "critical STS" makes it perhaps more fitting for the study of settings in which the stakes seem rather evident, the "sides" are clearly divided and the normativities involved are somewhat crystallized, that is, where the issues of the environment, class, race, etc., as listed by Hess and mentioned above, are dominant. Yet, it may also be that such predefined loyalties risk reenacting

predetermined normative positions, rather than opening them up, and produce what Hess himself calls "'good ethnographies' [which] frequently interrogate or complexify the taken-for-granted, such as commonsense categories employed by social scientists, policy-makers, activists and scientists" (Hess 2001, 239). Critical STS thereby runs the risk of first reenacting and then critiquing the "usual suspects" in a controversy, rather than empirically unpacking, complexifying, and resituating the normativities (and an author's own loyalties) in particular events. This need not be the case, of course, as more interesting studies in critical STS unpack their field of analysis, analyzing differences within a particular "social movement" (cf., Hess 1997). Such unpacking, however, must follow from an attachment to a particular agenda rather than being a core aim of the research practice.

According to Roland Bal and Femke Mastboom, this limitation of the critical STS notion of intervention is partly a consequence of the notion of "membership" as deployed by Collins and Martin: "The idea of 'membership' too easily misses that there is a lot of heterogeneity within a practice; that we, as all others, have to make choices as to where our priorities lie and what goals we want to pursue" (Bal and Mastboom 2007, 262). This implies that the critical STS notion of intervention may pose problems for the study of practices where the "core" of the issue is not clearly articulated (or where it is, and the role of the STS researcher would be to increase complexity) and where all actors are, in some sense, "working the peripheries of each other" (ibid).

Another reason for these limitations of the critical notion of intervention may be the strong connection between critical STS and controversy studies. The work on studying controversies partly draws on the assumption that the study of Science and Technology is ideally located in controversial events for this is where the STS researcher gets insights into otherwise disclosed mechanisms. Following this assumption, a concept of intervention that strongly draws on the positions that may be taken within controversies could potentially be equally applicable to less controversial settings. If, however, we realize that controversies produce *crucially different networks* than those that would be encountered when issues and positions are more complex and multiple, then this has farther-reaching consequences for a notion of intervention that draws heavily on controversial settings: the critical notion of intervention may then be more often problematic than helpful.

For these reasons, the notion of intervention that I will explore in this article is, on one hand, close to the third conceptualization proposed by Brian Martin; that is, it is dealing with the interplay of developing an

understanding of a field while at the same time trying to change it. On the other hand, it proposes a different pathway for locating normativities; that is, not situating them in predefined social problems (that then might need to be complexified), but rather locating them in the complexities of the practice that the STS researcher is trying to "act with." I hope to show that this approach to intervention, which I will refer to as "situated intervention," is an equally strong reply to the critique of the normative deficit of STS, that avoids reducing the space to explore and complexify multiple normativities.

With this theoretical aim in mind, I now turn to the question of *how* situated interventions may develop in practice. I address this question by analyzing my involvements in the development of the HCC.

Reconfigured Care, Different Patients, Changed Doctors; Toward Home Treatment of Hemophilia

Hemophilia is a bleeding disorder where patients are prone to bleeding due to a deficiency of coagulation factors in the blood, which are responsible for blood clotting. Bleeds can occur either spontaneously or after intense activity. With the development of medication to substitute for lacking coagulation factors, the duration of treating a bleed has decreased from several days or weeks of hospitalization to almost immediate results after injecting this medication. This development has cleared the way for one of the most remarkable transitions in the history of hemophilia treatment: the change from hospital treatment to home treatment.[11]

Whereas, until the early 1960s, patients had to be treated in a hospital by having their joints immobilized and by receiving blood transfusions to allow a bleed to pass or, from 1966 onwards, by receiving concentrated blood products such as cryoprecipitate,[12] they can now undergo a training where they learn to self-diagnose bleeds and administer coagulation factor concentrates at home, either ad hoc or as prophylactic treatment.[13] Since virtually every severe patient undergoes this training, the vast majority of bleeds of hemophilia patients is no longer treated *in*, but *under the supervision of*, a HCC.

With the displacement of hemophilia treatment from the hospital to the home (or work, holiday, etc.), medical professionals had to adjust to their new role of long-distance controllers of care. They witnessed the occurrence of a substantial discrepancy between the treatment they advised and the actual practice of patients treating themselves at home. Care professionals therefore started to see the issue of "compliance" of patients to treatment advice as a key problem of home treatment.[14]

I became involved in research on this topic when the care providers of a Dutch HCC approached the research group that I am a member of.[15] Due to a major policy change, these physicians were facing the need to restructure the organization of hemophilia care in the Netherlands. Care for a disease with such a low incidence was considered to be too thinly spread over the country to ensure good quality health care, the Ministry had decided to cluster hemophilia care in a small number of HCCs. Because no one knew which services such care centers should offer, the Minister of Health had asked hemophilia doctors to define what was crucial for assuring the quality of treatment. The Dutch Federation of Hemophilia Doctors specified a number of requirements, such as having a multidisciplinary care team, a guarantee of providing care twenty-four hours a day, regular consultations with patients (once per year, minimum), and a treatment plan for each patient, indicating the preferred treatment for the specific, individual patient, per type of injury. The Minister then set these requirements as a norm for the care to be provided by HCCs and appointed sixteen such centers (Borst-Eilers 1999). She thereby presented hemophilia doctors with quite an "implementation problem" for this new policy; virtually no center was able to live up to this ideal.

The doctors of one of these newly appointed centers wanted to "hire us in" (Downey and Lucena 1997) to assist them with the implementation of this policy change. During one of the first meetings, the physician who was our main contact in the project told me that his foremost concern was the situation of home treatment because, as he put it: "nobody actually knows what's going on there." Care providers were still responsible for treatment taking place in the home setting and expressed a serious concern for the risks that follow from undertreatment, including long-term joint damage and—potentially—the death of patients. With the change to home treatment, health care professionals had done their best to make the patients feel responsible for their own treatment, but in a psychological and legal sense, they still carried their responsibilities as deliverers of care. During a meeting, a hematologist told me the tragic story of a patient who was recently brought into the hospital in critical condition. He had bumped his head against his garden shed when getting on his bicycle to leave for work that morning. He returned inside and gave himself only about a third of the amount of coagulation factor concentrates that was prescribed in his treatment plan in case of a head-bleed. At work, he became unwell, and by the time he was brought to the hospital, it was too late to save his life. This hematologist also used this example of a preventable and quite clumsy death, to show his medical students that

accidents can happen—with drastic consequences—and to stress the weighty task they will face in enhancing compliance.[16]

Besides the obvious problems of undertreatment, doctors and nurses similarly feared the risks of overtreatment since they were constantly maneuvering within a setting where medication and funds were scarce.[17] The blood-derived medication is dependent on the availability of donor blood, of which there is a general shortage.[18] Although the introduction in 1993 of so-called "copy-DNA" or recombinant coagulation factor concentrates potentially provided an unlimited supply of safe medication, this promise has not been redeemed. Recombinant coagulation factor concentrates are not made from human blood but through DNA manipulation of hamster cells. This reduces the risk of all kinds of infections and supply problems that are implied in using human products. Quite regularly, however, pharmaceutical companies announce problems in the production process with the result that their products may be unavailable for several months. Although blood-derived medication with the same effect is generally available, it is risky to make patients switch between products. They may develop an inhibitor to all coagulation factors, which makes all treatment largely ineffective, and for young patients who have only used recombinant medication, switching to blood products means being exposed for the first time to all associated infection risks.[19] Therefore, doctors and nurses must take strong action in case of a supply problem to assure that recombinant products are at least distributed to children and only to change the medication of older patients (back) to blood-derived clotting factor.

However, even if availability of products is *not* a problem, care providers (and patients!) are still sensitive to the financial aspects of treatment with extremely expensive medication within a publicly funded health system. At various occasions in the project, both providers and patients stressed the exuberant costs of treatment per patient, per year, being several tens of thousands of euros. Both doctors and patients compared treatment to "shooting up a Mercedes [Benz] a year" and were well aware of the implications this has for public budgets.

Ways of Dealing With Noncompliance

Noncompliance has mainly been seen as a *problem per se* in literature on the treatment of chronic diseases. In *Tools of Care*, Dick Willems states that this has resulted in the situation in which: "compliance enhancement has become a basic principle of good medical practice" (Willems 1995, 126). The prevalence of compliance enhancement initiatives, however, is hardly

any guarantee for its success. As a recent review of randomized controlled trials (RCTs) of enhancement interventions shows, low compliance with prescribed treatments is seen as "ubiquitous," and the authors conclude that "the full benefits of medications cannot be realized at currently achievable levels of adherence; therefore, more studies of innovative approaches to assist patients to follow prescriptions for medications are needed" (McDonald, Garg, Haynes 2002, 2868). It is rather ironic that this conclusion follows an extensive literature search that has shown that: "even the most effective interventions [to enhance compliance] had modest effects" (McDonald, Garg, Haynes 2002, 2868). So even though striving for full compliance as an optimal state of treatment has proven extremely problematic,[20] it can still be seen as the dominant assumption in medical literature, with more enhancement tools and maximum compliance as the undisputed goal. This assumption is key for the dominant repertoire on noncompliance that I would like to call the *repertoire of distrust*.

The Repertoire of Distrust

In compliance literature, noncompliance is often analyzed in terms of the "underlying cognitive mechanisms" causing the "problem": "Patients *forget* their medication, they perhaps have an unspoken *resistance* against it and *think the disease is over* the moment they don't suffer from it any more"[21] (Willems 2001, 64, italics in the original). In accordance with this, attempts to enhance compliance are often expressed in a terminology that produces an: "atmosphere of unmasking, of distrust and of authority" (Willems 1995, 127). These cognitive explanations result in strategies for improving both patients' knowledge of their disease, and their attitudes, by providing better information on treatment. Information flyers are not the only resource of this repertoire. In the treatment of chronic diseases, treatments plans, medication journals, examinations, diplomas, and the signing of contracts by patient and care provider are common interventions focused on improving patients' knowledge of their disease and overcoming cognitive hindrances to being fully compliant. An interesting feature of this repertoire is that it mainly focuses on what I would like to call *treatment as planned*; treatment as defined in treatment plans, at a considerable distance from the practices of care delivery. It is this distance in the repertoire of distrust that seems to produce *evidence-based failures* for dealing with the issue of compliance. Being familiar with STS critiques of this repertoire of distrust, I took the low success rates of these compliance enhancement

initiatives as a starting point to reflect on the *causes* for this poor track record, for which I turned to *home treatment as embodied practice.*

Events in Hemophilia Home Treatment

In the improvement project for the HCC, there was no need to introduce this empirical turn to practices of home treatment like I introduce it here in the article: I was strongly encouraged by the health care professionals of the HCC to study patients at home. From their practical experience that patient and care provider annually negotiate a treatment plan that is sensible for both, while treatment practices deviate substantially[22] from this negotiated plan, they were highly interested to find out *what was happening* with treatment in the homes of patients. On top of that, in the case of hemophilia treatment, health care professionals have a somewhat unusual position. The chronic patients are very experienced in dealing with their disease, while hemophilia doctors often change the scene: due to its low incidence, since the policy change hemophilia treatment is concentrated in care centers, many of which are situated at university medical centers. *Scientifically* however, the development of treatment methods is rather unexciting. For doctors, there is therefore not much to gain by specializing in hemophilia care. This leads to a fairly high turnover of doctors and a more fixed and central position for patients.[23] As one patient described the position of one of the care providers in the HCC "This doctor has just recently joined us." In this setting, researching the practice of home treatment was seen by health care professionals as a welcome experiment that could perhaps help them alter this balance slightly. Interestingly, such "empowerment of doctors" would be an unlikely aim for critical STS with its relation to social and patient movements. Yet, it seemed to be one of the interesting normative complexifications that stemmed from the specificities of this care practice.

Following a route proposed by various STS authors (Conein, Dodier, Thévenot 1993; Thévenot 1993; Willems 2000), I decided to focus the analysis of present practices of home treatment on how humans and nonhumans share the coordination work that is needed to bring about a particular practice of home treatment. Furthermore, I followed a call for symmetry in studying both events of noncompliance as well as compliance as phenomena needing further analysis (Willems 2001).

Situated (Ir)rationalities

> P: If you want to get a piercing done, and you want it to work out all right, you will have to take a considerable boost of clotting factors. I think that's going too far; shooting up €500,—just for a piercing.[24]

An internist from the largest HCC in the Netherlands who I encountered during the project was rather cynical about the competence of patients to treat themselves. When I told him we were interested in observing and interviewing patients during home treatment, he mentioned that at home "patients are just doing whatever they like." This statement turned out to be quite far off the mark. One of the first things that became clear during the observations and interviews was that those who have a chronic illness spend a relatively small period of time in their role as patient.[25] They have to combine a variety of "social worlds" in which they play various—not necessarily complementary—roles (Clark 1991, 1997). It was obvious that the homes and settings of hemophilia patients are quite different from the previous locus of treatment: a university hospital. This insight was of course nothing new, and care providers had realized this when home treatment was introduced. It was therefore embedded in the abovementioned regime of a training program, an examination, and the signing of a contract by the patient. This served the aims of facilitating "correct" treatment at home and ensuring a clear distribution of liability:

> P: Before I started home treatment I got some kind of training in injecting. They checked if I was doing everything correctly. It was mainly practical. When you're treating yourself at home, you shouldn't panic. The chance of reactions [to medication] was larger then, but I wasn't suffering too much from that. It was a risk that you took home, though. So you had to be sure you could deal with it. What I remember most were the practical things: whether you put the stuff down neatly and whether your fingers were clean. And of course it was also there to diminish the risk for the doctor as much as possible, because if things went wrong the doctor could point out: 'look, it's not our fault, because we have been telling you this a hundred times.'

Various interventions in the development of home treatment have been geared toward formally distributing legal responsibilities or toward informing and educating patients about their treatment. There is, however, a problem with the temporality and spatiality of these interventions: they are introduced at a particular time and place while they should have their effect

at a later time in a radically different location. It is this time and space lag
and the absence of (a connection to) the intervention in the actual event of
treatment that often renders it useless. The absence of a sociomaterial con-
nection between the actual events of treatment and these initiatives deprives
them from their potential to coordinate the various roles hemophilia patients
are playing.

Within the repertoire of distrust, the medically situated view on
(ir)rationality and its concurrent disciplining tendencies suppose unknow-
ledgeable patients who are unable to be "'model patients'' with full compli-
ance—and who ignorantly harm themselves. We found that patients realize
quite well that such ''models'' exist but that their deviations from them are
often far from arbitrary or resulting from incompetence or cognitive
destructive tendencies.

> P: I run my own business, which means that my time is very valuable. And
> since my health is relatively good, I don't like unnecessary investigations.
> I want to have a few purposeful things examined, but not for the sake of
> research. I've made good agreements with doctor Johnson about that. So,
> as far as that goes, I might not be their model patient. I'm calm, so in that
> sense maybe I am, but what they like most is to see everybody to do all kinds
> of nice exams every half-year. I've reduced that to once a year. And that's
> good enough for me, because I told them I would always come by if some-
> thing was wrong. Every year I hear the same thing during check-up. I need
> them for the stuff, and as a back-up in case something goes wrong.

The ''model'' that patients should adhere to meets strong competition
from other worlds in which the patient plays a part and that enact different
expectations of patients.[26] These other roles may seriously put the ''alli-
ance'' between HCC and patient—that is needed to live the role of hemo-
philiac—to the test. During the interviews, several patients mentioned
situations in which the demands of others were perceived to oppose the
demands of treatment, for example when taking part in their gym class at
school or when a patient felt he should participate in a decathlon that was
organized by his neighbors. However, the alliance also, at times, received
unexpected support where it could have been fractured.

> P: A few weeks ago, at school, we had to lug a bunch of tables from the first floor
> downstairs for an exam, and then I will carry them as well. That shouldn't be too
> much of a problem, but there were a few colleagues who said 'why don't you do
> the corridor, then we'll do the stairs.' Then I think, yes, they've got a point there.

In this case, the role of being a good colleague is about to come into conflict with that of being a hemophiliac: the school setting, together with the obvious urgency of getting things ready for an exam, challenges the durability of the alliance between this patient and the HCC. It has been noted that "improving the success of a treatment programme not only demands strengthening the alliance between patient and programme but also between the programme and the patient's relatives and other significant persons" (Willems 1995, 135). This means that persons, in this case colleagues, can help coordinate the roles and worlds that need to be brought together.

Delegating the construction of alliances to humans may be a fruitful approach in some respects but solely including humans may also limit the durability. Similarly, defining noncompliance as a "cognitive problem" ignores how coordination can be obstructed by sociomaterialites.

> P: I was still working in an office then. I would take factor VIII that was being kept in the fridge there, with my name on the bottle. When I would get a bleed, I would stay inside the building. They reserved a separate room for me for this purpose. This saved time.

In order for treatment to be carried out safely, it is important that a second person is present to intervene in case of an allergic reaction to medication. This need discords with the specificities of the workplace: the desire for privacy and the corporate ideal of productivity of labor are in this case afforded at the expense of the safety of hemophilia care.

Symmetrically studying the mysteries of both noncompliance and compliance proved highly fruitful for gaining understanding of the complexities patients face when they must coordinate very different worlds in the practice of hemophilia home treatment. These insights were valuable when experimenting with interventions to change these practices. To define which interventions could be relevant and interesting here, there was no clear controversy in which to position myself. There certainly were attachments to the idea of moving away from the ideal of full compliance. Both my analysis on the complexity of social worlds, and that of other STS researchers (Clark 1991, 1997; Willems 1995), made me aware of the unreasonable and impossible price patients would have to pay to achieve this medically defined ideal of treatment. Yet, my study of the care practice had indicated that the doctors, rather than the patients, seemed to be marginalized in hemophilia (home) treatment, which provided some interesting complexity to our normative attachments. In the process of "sorting" these attachments (Jensen 2007), we realized that the experimental interventions

should neither aim at an uncritical and unspecified enhancement of compliance nor celebrate the complexity of social worlds and explain noncompliance. Rather they should contribute *to targeted forms of coordinating the various worlds patients inhabit in those instances where it seemed to matter most*. The experiments we were involved in consisted of a range of developments, including the design of a digital version of the logbook with data on medication that were administered at home and of a web portal for communication between patients and HCCs. However, here I will focus on two rather modest, yet effective, interventions: first, the introduction of a small but powerful technological device (a temperature logger), and second, the development of the organizational intervention of setting up a multidisciplinary hemophilia consulting hour.

Experiments in the Practice of Hemophilia Care

As we observed during the study of home treatment, by far the most problematic coordination of the various worlds patients inhabit occurs during vacations. With the introduction and development of coagulation factor concentrates, it has become possible for patients to bring along medication to their holiday destination and carry on their treatment in a place that is even more remote from the hospital than the usual home treatment setting. Despite this substantial relocation of care, patients are expected to treat themselves at their holiday location the same as they would at home or rather, as they would in the hospital. On top of that they should provide suitable conditions under which medication is stored while being transported and during their stay. In addition, these conditions are quite demanding: in order not to lose its efficacy, coagulation factor concentrates should be kept in a cool place, preferably a vibration-free industrial refrigerator. With the displacement of care to the holiday setting, the norms of professional cooling equipment, the careful chain of transport before the medication arrives in the center,[27] and all the safety regulations that a hospital pharmacy must adhere to are substituted by a portable cool box or a small daypack that is equipped with a cooling compartment and removable cooling elements. This delegation hardly coordinates the worlds of the hemophiliac and the holidaymaker, which sometimes leads to serious treatment problems.

> P: I had an ankle bleed over there [at my holiday location] that lasted for almost a week. In that week I took a lot of medication. For four weeks, I sat at four different campsites and used the same chair the whole time. I shot up

> 2000 units every day, but it wouldn't pass. We looked for a treatment center in the area after two or three days, but it started to improve slowly. The medication probably didn't work because it was stored in a place that was too warm. We kept the medication in a separate bag with cooling elements, but it was over 30° Celsius outside. I think that we should have exchanged them every day, and I must have forgotten. I've been sloppy with that.

> I: Could you check afterwards if the temperature had actually been the problem?

> P: No, I haven't checked.

The sociomateriality of beaches, campsites, high temperatures, cooling elements, and laidback holidaymakers provide strong challenges to the effectiveness of this event of hemophilia care.

Hot Dogs in Hemophilia Care

In the analysis of practices of hemophilia home treatment, it was further specified for whom these tricky treatment events during holidays were actually "problematic." Of course it could be argued that this state of affairs is only problematic from the position of the hemophilia doctors, while it looks celestial for those propagating the "autonomy" of patients. Within this repertoire, any intervention would be an illegitimate and unfair way of disciplining patients. Although this may sound like an unlikely position, this is exactly the critique I received when presenting this material at an STS forum. The question that was critically raised was "But aren't you just disciplining the patients?!." The point here however is that disciplining per se is not a problem if one does not fix oneself on an antimedicalization agenda. The question rather becomes "which disciplining interventions are justified for which actors?" And in this case, even when taking the extreme position that patients should have the "freedom to die"—which would be the ultimate risk of treatment with ineffective medication—this freedom may have implications for the risk other patients face during treatment. In the case discussed in the quote, the patient did not merely use large amounts of factor VIII; the medication was also exposed to high temperatures, while the patient did not check if the medication actually lost its efficacy. Since clotting factors that are not used on holidays are returned to the HCC and administered to other patients,[28] this means that his "freedom" actually jeopardized the effectiveness of the treatment for other patients. This

Datalogger HOTDOG DT1

Working range −40°C...+65°C, waterproof (measuring), 0°C...+50°C (evaluation):

Memory capacity: 16,000 measured values

Time ranges: 2.2/4.4 hours to 500 days

Measurement interval: two seconds to two hours

Figure 1. Temperature Logger.

situation warranted the situated disciplining of patients and it seemed worth experimenting with an intervention that would enact the world and responsibilities of the hemophiliac more strongly, thereby enhancing compliance on how medication is supposed to be handled.

It was the hematologist who was involved in the project who pointed my attention to a device that might play an important coordinating role here: a TechTemp temperature logger of the Hotdog model that registers temperatures at regular intervals (see figure 1). We started an experiment to see how these loggers could enhance the proper handling of medication. The loggers were included in the holiday package that contained the medication, and this package was sealed in a plastic bag. Patients were notified that a temperature logger was included in their holiday pack and that upon returning unused medication, the temperature to which the products had been exposed would be checked. I wrote a small research protocol for the pilot that included the rule that every time one of the two loggers was available, it would be given to the first patient who requested a holiday pack.

This experiment had two interesting results. First, several times, the medication that was returned had been exposed to temperatures that were unacceptable according to the instructions for use. This came as a surprise to the nurse, since she had actually been unhappy about the fact that every time she had to hand out a logger, this was to a patient who she perceived to be very reliable. Her expectations concerning reliability were

influenced by both ethnicity and holiday destination: a middle aged native Dutch man, going on a short holiday to France was expected to be more reliable than a Moroccan man driving to Morocco for a six-week holiday during summer. She now feared that the experiment would fail since nothing would go wrong and no interesting data would be produced. Although we could never assess the appropriateness of her expectation, it was interesting to see that ''reliable patients'' were exposing their medication to high temperatures.

Second, the logger, though actually only registering temperature, also proved to be quite an intervention, changing how patients were handling medication. A particularly ''reliable'' patient, who surprised both the nurse and himself by having exposed the medication to excessively high temperatures during his first journey, received the logger some months later when coming for another holiday pack. Upon returning from this second trip, he was quite sure that this time nothing had gone wrong with the medication but this second pack actually had to be thrown out, as well. This time it turned out that the medication had been exposed to temperatures that were *too low*—it had been frozen. He placed the medication in his ski box on top of his car on his skiing holiday, also when traveling, and during the night, to ensure a cool environment. Although the result for the medication was the same, in the sense that it had gone to waste, this event indicates that the logger can be a powerful actor. Including it in holiday packs is consequential in the remote landscape of a holiday setting. It proved capable of facilitating coordination between the worlds of strict safety regulations on one hand and that of holiday relaxation on the other, through its temperature measurements. Even when medication was exposed to temperatures that had been either too low or too high, this no longer jeopardized the effective treatment for other patients, thereby confining the risks of inappropriate handling of medication to the individual patient.

Although adding the logger to the vacation pack influenced the actions of this patient to a certain extent, it did not prevent the medication from going to waste. A discussion that now becomes pertinent is whether the world of the ''hemophilia patient'' may be performed even more strongly by developing a logger that does not merely register temperatures but that also acts—for example by beeping—on behalf of the HCC when the medication is about to be exposed to a temperature that is either excessively high or low. This could prevent wasting scarce medication. Whether such an extended coordination mechanism would be too much of a disciplining intervention for vacationing patients, or can be justified by referring to the risk of using ineffective medication to treat future patients, is at present

unresolved. The argument of scarcity is valid here as well, and it seems that in this particular setting, this stronger intervention would be warranted.

Some tensions that may emerge from this experimental intervention are that to actually provide functionalities like alerts, we would either have to look for other loggers that are able to do this or get involved with a redesign of the loggers, which, as Diana Forsythe has beautifully shown in the case of the design of an information system for migraine sufferers (Forsythe 1996), would provide all kinds of other constraints of intervention and design. In addition, though the logger may at times be a lifesaver, it may also lead to shifting both responsibility and cost completely to hemophilia patients.[29] When the costs of medication that has gone to waste would be claimed with patients, this could on one hand be seen as a strong incentive for enhancing compliance, but it would need to be analyzed in the light of strong enactments of self-reliance for hemophilia patients. Patients are taught, for example, to be self-reliant in survival camps that are highly praised by hemophilia doctors and the patients' association alike. When discussing this rather counterintuitive practice of young people with a bleeding disorder doing hazardous activities like rappelling, the pediatrician from the HCC, nor the representative from the patients' association saw any conflict. Rather, they stated, this was an important moment for these young individuals to break out of the overprotective atmosphere that their parents often created for them. I was clearly unable to "intervene" here, since I was unable to articulate the camps as at least partly problematic—even though the camps are sponsored by pharmaceutical companies, who are of course not disinterested in enacting patients as "self-reliant" and "'certain," especially when these "selves" are enacted by the practice of (expensive) prophylactic home treatment. Similar shifts in responsibility and discipline, combined with availability of products that was previously unthinkable, has been analyzed elsewhere in relation to the "epidemic" of obesity in the United States. It has been noted that

> [T]he neoliberal shift in personhood from citizen to consumer encourages (over)eating at the same time that neoliberal notions of discipline vilify it. Those who can achieve thinness amidst this plenty are imbued with the rationality and self-discipline of perfect subjects, who in some sense contribute to the more generalized sense of deservingness that characterizes US culture today. (Guthman and DuPuis 2006, 427)

Although such ironic interplays of performing self-reliance at a rather high cost (possibly even financially) are worth further investigating, for now this experiment has proven fruitful in raising questions about which

forms of autonomy can be enacted in the case of hemophilia treatment. It also points out which further experiments could be carried out.

The example of the temperature loggers shows that interventions in the coordination of care can fruitfully be combined with the normative sensitivity that is engendered by STS work on compliance and the possible role of small technologies in coordinating complexity in home treatment practice. But the experiments were not limited to small technological devices. The role of the hemophilia nurse seemed of exceptional importance during the analysis and therefore seemed to warrant further articulation.

From "Chatting With Patients" to "Running a Clinic"

Continuous mild interferences in treatment came to the fore when observing the interactions between hemophilia nurses and patients who came to collect their medication. Although handing out medication could be seen as a routine task that could be carried out by any qualified pharmacy employee, the nurses insisted on doing this ''unfitting'' work themselves—to the great dissatisfaction of nursing management and other nurses on the ward, who qualified these conversations as ''chatting with patients.'' Based on an increasing focus on medication safety and quality control systems in the hospital, there were strong pleas for transferring this distribution of medication to the hospital pharmacy or even to deliver medication to the homes of patients. During the casual exchanges with patients, hemophilia nurses often found out clinically relevant information concerning their situation—such as stress for an exam—and could give treatment advice accordingly. Being sensitized through the publications of various STS scholars (Suchman 1995, 2000; Star and Strauss 1999) to the importance of articulating and accommodating ''invisible work,'' I realized that rather than adhering to the pleas to stop the nurses from running their own pharmacy, this work could be legitimated by providing a formal space for such encounters.

This contributed to installing a multidisciplinary hemophilia clinic, which included a nurse-led clinic and a clinic for the physiotherapist. This clinic is an example of an intervention that seemed of substantial importance for coordinating and negotiating the worlds of hemophilia patients and other roles. The aim of the consultation was not merely to inform or ''educate'' patients further but to formalize the role of the hemophilia nurse in communicating with patients to spot emerging difficulties. Furthermore, by scheduling this clinic parallel to the surgery hours of the hematologist, cooperation between the patients and the hemophilia nurse and between the

nurse and the hematologist were intensified. Here, the threat to the legitimacy of nurses taking rather substantial and nonstandardized action in guiding patients did not come from clinicians defending their professional autonomy. Doctors, especially those in training, were quite used to situations where a hemophilia nurse would correct their prescribed treatment, since these nurses simply had much more expertise on these matters. Rather, the threat came, perhaps unexpectedly, from colleagues who saw the hemophilia nurses as excessively self-dependent and insufficiently integrated in the totality of the ward (Zuiderent 2002). Although the installation of the hemophilia clinic may seem to be a rather minimal intervention, it was quite consequential for the situated normativity of legitimized nursing work on the ward.

A final advantage of installing this hemophilia surgery hour was that hemophilia patients, who were previously seen by various doctors during different surgery hours that were distributed over the week, would meet again at least while waiting for the consult with the hematologist, or hemophilia nurse. In the days of hospital treatment, patients also brought issues to the hospital that were relevant for how they were living with their disease. This not only hospitalized the patients but also socialized the hospital—a situation that has been described elsewhere as "'smuggling' patient perspectives and competences into the daily work of the physician" (Willems 2000, 29). Bringing patients and health care professionals back into more structured contact might help reconfigure the distance[30] that has arisen between HCC and patients as a result of the development of home treatment. Refiguring this distance might facilitate the shift from mere compliance enhancement toward finding ways of coordinating the complex worlds that might collide in treatment practice.

I tried further to explicate the aims of the clinic as a place to discuss the complexities of coordinating different roles, rather than merely to discuss "patient issues" to both patients and health care professionals, by addressing this issue in a talk I gave at the official opening of the HCC. By quoting their statements from the interviews and affirming that it simply cannot be expected that they are "model patients," I presented the consultation as an opportunity to discuss the complexity patients face during home treatment. What I tried to point out to the actors in the HCC is that on the one hand "hiring in" is related to the "willingness on the part of social researchers to allow their work to be assessed and evaluated in the theoretical terms current in the field" (Downey and Lucena 1997, 119) while on the other hand it is crucial for interventionist research (to be different from consultancy) that there is a mutual willingness and interest of the various parties to be inspired

and "contaminated" by each other's practices. I would claim, however, that for interventionist research to be different from consultancy, there should be a *mutual willingness* and interest of the various parties to be inspired and "contaminated" by each other's practices. On this note, I return to the consequences of these events for conceptualizing intervention and normativity in STS research.

Useful Risks of Artful Contamination

I hope to have shown that the experimental interventions in the practice of hemophilia care were strongly related to STS research on compliance and medical practices, to the coordination of worlds that patients live in and to studies of making work visible. The conceptual and practical critiques on interventions aiming at mere compliance *enhancement* have been an inspiration for experimentally intervening in the *kinds* of compliance that can be enacted in particular treatment events, such as compliance to medication handling in a vacation setting. Considering the complexity that people face in combining their role of "being patient" with the other roles they play makes full compliance equally unattainable and undesirable. This made the experiments that dealt with a particular (and particularly problematic) issue in hemophilia home treatment interesting to both me and the health care professionals of the HCC. By rejecting the notion that compliance is something medical practices should have "more" or "less" of, interventions can be assessed on the basis of their contribution to the coordination of the worlds patients inhabit and can be used to indicate in which instances stronger compliance enhancement may be worth pursuing. Furthermore, studying the invisible work hemophilia nurses were doing allowed me to articulate this work in the more legitimized setting of a nurse-led clinic, rather than following the line of argumentation voiced by the hospitals' (quality) management that the work of handing out medication should be relocated to the hospital pharmacy.

To this extent, I hope to have shown how these interventions are connected to STS research. This does not mean that any skillful sociologist, engineer, or health care consultant could not have come up with the same interventions; they may be similarly sensitized to emerging normativities and opportunities for situated compliance enhancement.[31] STS has not delineated unique forms of expertise based on which an intervention can be claimed to be an "STS intervention." Yet, the interventions in this case were certainly shaped by a figuration of compliance that is crucially different from the repertoire of distrust. This shows that STS researchers may

not have unique forms of expertise but certainly have a rather well-developed sense of the interplay of sociomaterialities and situated normativities (Law 2004).

At the outset of this article, I proposed to explore a situated normative approach that would be a convincing reply to the critique of constructivism being ''normatively deficient,'' though without relocating the normativity of STS in agendas of social problems, activist movements, and the democratization of technology. I also proposed that the approach of situated interventions that focuses on complex and emerging normativities would possibly be more fruitful for studying practices that would not easily be typified as ''controversial.''

In the light of critiques that STS has difficulties in overcoming its ''normative deficit'' (Keulartz et al. 2004), it is interesting to note that the situated interventionist experiments described here seem to make the issue of normativity fairly ''easy.'' This does not mean that interventions are in any way predictable and certain; as Donna Haraway keeps reminding us, ''[t]here are always more things going on than you thought'' (Haraway 2004, 332), which makes the nature of any intervention extremely tricky (Haraway 1991). Yet, an ethnographically inspired analysis of these practices of hemophilia treatment seemed to facilitate exactly what Hess promotes: it allows one to ''interrogate or complexify the taken-for-granted, such as commonsense categories employed by social scientists, policy-makers, activists and scientists'' (Hess 2001, 239), producing a normative space that may well lead to positions that do not fit predefined normative agendas. Through such an analysis, doctors, instead of patients, turn out to be marginalized, nurses are shown not to be suppressed by clinicians striving for autonomy, but by their colleagues who want them to stop ''chatting'' and get back to work, and patients are found to be self-reliant to such an extent that this produces unwarranted risks to the safety of the patient collective. These are not quite the usual normative suspects but are, rather, a set of normativities that clearly facilitate situated experimental interventions. Normativity was found neither by assessing the democratic involvement of patients in shaping the care practices nor in critically assessing the roles of care professionals who were disciplining patients through intrusive devices such as logbooks. Rather, experimentally analyzing patients, campsites, doctors, loggers, nurses, and hospital clinics with respect to the practice of hemophilia home treatment turned out to reveal unexpected normativities to ''act with'' as well. The experiments therefore show an interesting way out of the normative deadlock of STS, not by introducing

external predefined normativities but by *relocating normativity in the complexity of the events of treatment itself*. Intervening in these events thereby becomes a way of *doing normativity*.

Based on the normative complexity encountered and enacted in the case of the HCC, I want to make a contribution to the study of intervention and STS that is broader than the focus on activism and democratization. The activist approach has proven fruitful for more controversial cases; however, it also runs the risk of *producing* some of the tensions that are encountered in the study of intervention. The "tension between the tendency to immerse oneself in the complexities of ethnographic detail and the tendency to produce an explicit contribution to a research tradition of theoretical models and empirical findings" (Hess 2001, 239) is not as vividly encountered in the study of situated interventions. Here, the only way to come to such explicit contributions is *through* immersing oneself in the normative complexity of practices. Rather than claiming that "[o]ne can maintain a high standard of descriptive analysis while at the same time providing grounds for making prescriptive recommendations" (Hess 2001, 240), this approach proposes that it is *only through* high-standard analysis that one can find situated grounds for experimental interventions.

Instead of drawing upon rather crystallized normativities of social movements, the approach of situated intervention allows for a position in which normativities of STS researchers are productively "contaminated." Drawing upon Chantal Mouffe's conceptualization of this term, a relation of contamination means that both STS insights and (health care) practices under study become entangled, and that changes in the domain and normativity of these practices change the identity and normativity of the domain of STS and vice versa (Mouffe 2000, 10). Although exploring such contaminating experiments may prove fruitful for situating interventions, there is always the risk that STS insights are subsumed (and any form of the critical edge is lost) or that all sensitivity for the complexity of practices is exchanged for "[h]eroic images of scholars as activists without double-bind [which] madden as much as they lure" (Fortun 2001, postscript: 2).[32] Downey and Lucena refer to such a danger as the "complementary risks of cooptation and social engineering" (Downey and Lucena 1997, 120). When STS insights become subsumed, "normativity made easy" would certainly overshoot the mark, because it would be simply an a-critical stance that reconfigures STS researchers as unreflexive "system designers" (Jensen 2008, 321). Paraphrasing Lucy Suchman's concept of "artful integration" (Suchman and Trigg 1992), interventions in the practices of STS analyses can be carried out with the aim of coming to *artful contamination*: a productive

interplay in which STS scholars are influenced by the practices they act with, without losing the ''anti-bodies'' they keep building up by being part of other practices, be those STS conferences, debates with activists or discussions in their research groups. Besides drawing upon a repertoire of reading and practicing what David Hess called ''good ethnography,'' artful contamination is to be developed by moving around. Preventing that the activities of interventionist STS research become sedentary is crucial to minimizing the risks of cooptation and social engineering. Maintaining many ''partial connections'' (Strathern 1991) to practices of care and practices of (critical) STS in the case of the HCC prevented me from either a-critically adopting the discourse of distrust in relation to compliance or viewing every compliance enhancement initiative as an unjust intervention in the complex lives of autonomous hemophilia patients. Moving around in care and STS opens up the complexity of both, reclaims normativity from the critics and the ethicists, and allows STS researchers to do normativity as a fruitfully risky business.

Notes

1. See for example: (Pasveer 1992; Willems 1995; Berg 1997; Dodier 1998; van der Ploeg 2001; Gomart 2002; Mol 2002; Callon and Rabeharisoa 2004).
2. Quoted in (Martin 1996, 266).
3. Qouted in (Hess 1997, 161).
4. I want to thank Brian Martin for pointing out this way in which captivity is sometimes wrongly understood.
5. For an account of how this interplay can be used as ethnographic material, see (Zuiderent 2002).
6. They do not elaborate extensively on this remark, but it seems they are making a point that relates to the ''Mode 2'' and ''Triple Helix'' discussions (Gibbons et al. 1994; Etzkowitz and Leydesdorff 2000), which are beyond the scope of this article as well.
7. Quoted in (Hess 2001, 236).
8. I have explored elsewhere some problematic assumptions of the democratization of technology thesis (Zuiderent 2002), particularly in relation to the way this debate has shaped the field of participatory design. Although discussions on the normativity of interventions in participatory design are relevant, these are outside the scope of this article because I primarily focus here on discussions of intervention in STS. For further critiques from the ''democratization debate'' within STS, see (Markussen 1996; de Wilde 1996; Berg 1998).

9. See for example, various contributions to (Downey and Dumit 1997a,b), and (Campbell and Eubanks 2004; Woodhouse and Patton 2004). I would like to thank David Hess for pointing out some of these core texts.

10. See for example, various contributions to the workshops organized by Steve Woolgar and colleagues in 2004 and 2005: (Woolgar et al. 2004, 2005) and the special issue of the journal *Organization* based on these workshops (16(1)), the contributions to (Zuiderent-Jerak and Jensen 2007) and (Wouters and Beaulieu 2007).

11. A change that only took place in Western Europe, North America, and Australia, because there is not enough supply of coagulation factor concentrates in other regions to treat patients in this manner at all.

12. A substance with a high concentration of coagulation factors obtained by freezing and melting blood plasma.

13. Prophylactic treatment is the treatment given to keep the coagulation factor in the blood on a high enough level to prevent bleeds.

14. Although beyond the scope of this article, it would be interesting to investigate compliance when treatment was mainly situated in the hospital. One would expect that "full compliance" would be equally absent.

15. This group was at the time called: Research on IT in Healthcare practice and Management (RITHM), and focused on the sociotechnical study of information technology and organizational change in health care. The reason they could approach us was that they had an offer from one of the pharmaceutical companies producing coagulation factor concentrates to finance research on the changes needed for hemophilia care centers. This fund was labeled by the company as "goodwill money" that, so they claimed, would otherwise be "spent on flyers."

16. In all, the empirical material presented, patients are referred to as "he." This is neither a sign of sexist language nor of some bizarre selection of empirical material. Hemophilia patients are all male: women can only be "carriers" of the disease.

17. It is worth noting here that *what* over- or under-consumption exactly is, is highly subjected to debate. This is evident in the international discussion on differences in national treatment policies (Steen Carlsson et al. 2003) and the importance that is given to prophylactic or ad hoc treatment in different countries.

18. On a global scale, there is such a shortage of medication that about 80% of the patients receives no treatment with coagulation factor concentrates or even blood transfusions at all (Mannucci 2003).

19. Although blood products are thoroughly screened to decrease contamination risks, the dangers of spreading unknown or "new" diseases can never be fully precluded. In the 1980s, many patients with hemophilia where infected with HIV. There is also a very high rate of hepatitis infections among hemophiliacs.

This makes patients extremely wary for being exposed to "new" diseases such as Von Creutzveld Jacobs Disease (vCJD).

20. Not merely because it is very hard to achieve, nor just because there is often substantial medical debate about *what* patients should comply to, but also because historically it can be argued that balancing the activities of a care provider prescribing only with "approximate accuracy" and patients complying with "only modest fidelity" has enabled mankind to: "survive bleeding, cupping, leeches, mustard plasters, turpentine stupes, and Panalba" (Charney [1975] quoted in Willems [1995, 134]). Limited compliance may similarly have been a life-saver for various hemophilia patients during the distribution of HIV-infected blood products in the 1980s.

21. Translation from Dutch: TZJ. Original: "patienten *vergeten* hun medicijnen, ze hebben er een misschien onuitgesproken *weerstand* tegen en *denken* dat de *ziekte over* is zo gauw ze er geen last meer van hebben."

22. Since they were very keen on having a quantification of this "substantial deviation," I asked for help of a colleague from my institute who analyzed the data that patients entered in their treatment journal, and that the hemophilia nurse typed into a database using SPSS software. Interestingly, these data had been collected but not analyzed before. The outcome showed that patients *with similar treatment plans* had *highly individual treatment patterns*. These findings were discussed with both health care professionals and patients.

23. This strong position for patients was further enacted by a very strong and influential patient association, the Dutch Association of Hemophilia Patients. With a membership rate of approximately 95% of Dutch hemophilia patients, they could act (and were seen) as a very strong agent.

24. The quotes that are used come from interviews with patients of one of the Dutch HCC's. These interviews were carried out by Gezieneke Aris, for which I am grateful to her. I have translated the quotes that I use into English and slightly edited them to improve readability. "P" stands for patient, and in later quotes "I" for interviewer.

25. Compare (Conrad 1985) quoted in (Willems 1995, 135) and (van Houten 2000).

26. It is important to stress here that *what* this "model patient" is within the HCC is similarly equivocal.

27. With pharmaceutical companies like Aventis Behring claiming on their Web site (www.aventisbehring.co.uk) that they have their own fleet of transportation vehicles, because delivering the medication following first class safety regulations is not to be outsourced: it is part of their core competence.

28. A practice that is actually not in line with the Dutch pharmacy regulation but is a pragmatic solution that can be found in all HCC's due to the high costs and scarcity of the clotting factors.

29. I want to thank David Hess for pointing out these tensions.
30. ''Distance'' is to be taken here in a metaphorical sense. This is worth mentioning, because the physical distance between patients and HCC's is a hot topic among the patient association, HCC's, and the Ministry of Health, who must find a balance between the standards a HCC should live up to and the need for a geographic distribution of centers.
31. I thank Brian Martin for pointing this out.
32. Quoted in (Hess 2001).

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Bio

Teun Zuiderent-Jerak is assistant professor of Science and Technology Studies in the institute of Health Policy and Management of the Erasmus University Rotterdam, the Netherlands. His research interests include interventionist STS, standardization and innovation in health care, the development of health care markets, and normativity as practice. In 2007 he completed his PhD thesis titled *Standardizing Healthcare Practices; Experimental Interventions in Medicine and Science and Technology Studies*. He has published articles in *Social Studies of Science, Scandinavian Journal of Information Systems, Human-Computer Interaction,* and *Science as Culture*, and has co-edited a special issue of *Science as Culture* on *Unpacking "Intervention" in Science and Technology Studies.*