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Annemarie Mol

Cutting surgeons, walking patients Some complexities involved in comparing

In health care most facts come as *comparative* facts. Few conditions or treatments are ever treated as simply *good* or *bad* – as if there were absolute standards. Rather, they are *better* or *worse*: than they were; than their alternatives; than an agreed threshold; than might be expected. Thus assessments involve comparisons. But this means that they raise the question what is similar and different between different situations. So how might similarity and difference be mapped? If we look at this closely it turns out to be complex rather than simple. In this chapter I explore some of the complexities involved in comparing treatments with one another – which also implies a study of another kind of comparison: that of the conditions of patients before and after treatment.

This is what lies behind my inquiry. Making comparisons implies simplification. But what kind of simplification? What is to be skipped, bracketed, smoothened or left out? And how might simplifications be made in such a way that the world isn't flattened? If we want to begin to get an insight into these questions, we also need to keep the *platforms* in view, the platforms upon which comparisons are made. So the question is: *where* are all the comparisons, and what are the *effects* of making them?

In this chapter I will explore these broad questions by looking at a single (simple?) case. This is a comparison of *walking therapy* and *operations* as treatments for arterial disease in what medicine calls 'the lower limbs'. The material for this study was mainly gathered in two university hospitals in the Netherlands, hospital Z and hospital G. There we (my research assistant Jeannette Pols and myself) spoke with medical professionals, technicians and patients and observed practices of diagnosis and treatment. We also read relevant medical literature, and spoke with general practitioners, physical therapists and patients working or treated elsewhere in the Netherlands.¹

Two treatments

A patient information leaflet in use in hospital Z:

“A vascular obstruction or an occlusion has been found in one or more of the arteries of your leg. (...) Due to these obstructions or occlusions less blood flows through your leg. This may cause pain in your leg when you walk which disappears again after a short rest. Even though not everybody in a comparable situation has to have an operation, in your case it may be the only way to relieve you of your symptoms.”

An operation may be the only way ‘to relieve you of your symptoms’ if you get pain in your legs when you walk. It may take such pain away. But operations are done for other reasons too. The same leaflet:

“It may also be that so little blood flows through your leg that you have pain even when you are resting or at night in bed. There may be ulcers that do not heal or a toe may have died off. In such cases an operation is necessary to improve blood flow through your leg. Without an operation it is often not possible to avoid an amputation of the leg concerned”.

So an operation may be done when wounds ulcerate and don’t heal. For if gangrene to set in, survival would require amputation: gangrene is deadly

The patient information leaflet in hospital G doesn’t speak of ulceration and gangrene. It only suggest walking therapy for people whose legs hurt when they are walking:

“You have been in the hospital for an investigation of your blood vessels. In the arteries of your legs one or more obstructions have been found. You have been advised to start to do walking therapy. (...) Because of the obstruction in the arteries of your legs, the latter start to hurt after you have walked a certain distance. In the end this makes you stop. The pain can be in various places in the leg: the hips, upper legs, calves or feet. The medical name for this problem is intermittent claudication. Walking therapy is a treatment for claudication which gives good results. The treatment aims to increase the distance that you are able to walk without pain.”

So these are the two treatments that are being compared here: operation and walking therapy. In the information leaflets they are not presented as treating the same problems. But neither do they treat different problems. Their indications overlap. Both may be used if your legs start to hurt as you walk and stop hurting if you rest.²

Reasons for treatment

But how much should your legs hurt, and how little should you be able to walk, before considering treatment? Patients are responsible for the first step in dealing with this question. For only if patients consider their own situation to be bothersome or worrying do they go and see a doctor.

*General practitioner: “There are always old people who say, well, it’s old age. I can’t walk all that well any more, but what should I expect? And then they never even come to see me, or any doctor, with complaints about pain when they are walking.”*³

So some ‘patients’ never even become patients. But others do. They come to see a doctor with their questions and their stories. These are not all taken into account. The consultation is a filter. Here, distinctions are being made. People who describe pain that only occurs when they are sitting are *not* classified as having vascular disease or intermittent claudication. And if they do have pain when they walk, then the question of *how much* pain is not explored. It is too hard to handle: people express and may even feel pain in different ways.⁴ Instead, what doctors want their patients to talk about is something simpler: the *distance* they can walk before their legs start hurting. Their so-called *pain free walking distance*. This is easier to communicate than the inexpressible amount of pain. For ideally it comes in standard numerical form. If we want to talk about distance we have the meter which was especially designed to facilitate comparison between sites and situations.⁵

However, one doesn’t need to talk to medical practitioners for very long before they start to tell stories about the way in which the intricacies of practice defy the ideal of numerical standardisation.

Angiologist (internist specialised in vascular problems) in an interview: “How far are you able to walk? In America they express this in blocks. That’s a fairly standard measure. We don’t have that. I ask: how far can you walk? ‘Yes, a good 100 meters, doctor’. ‘At a reasonable pace?’ ‘Oh, yes, sure’. And then, if you walk along with them, such answers appear not to be correlated at all with the actual walking distance you find”

People do not live their daily lives in meters, but think of the distance they can walk as ‘too little’ or ‘from our house to the corner’. In the translation from such experiences to a medical assessment of ‘pain free walking distance’ things may get lost. And once numbers are scribbled in the patient’s file they come to have an independent existence as ‘indicators’. Possible errors of translation are no longer retrievable. Nor is the tone of voice (confident, hesitant, pleading). So some complexities are left out but something is also gained, for numbers are easy to handle. The numbers that belong to a patient are comparable to those of other patients and to agreed thresholds (above or below which further investigation is indicated).

Numbers may be mapped on a linear scale: a graph may be plotted of individual metricated walking distances. In research and clinical trials there are overviews of this kind of many patients and the way in which their conditions did or did not change (without or after treatment). But in clinical practice linear scaling is not usually the way of handling the numbers that express ‘pain free walking distance’. For here there is little distinction between 50 and 60 meters: both are pretty bad. And to clinicians the difference between 50 meters and 100 meters is far more ‘impressive’ than the difference between 300 and 350 meters. In practice, often a potentially numerical linear scale is dissolved into a few classes. Sometimes there are two of these, as in ‘normal’ versus

‘pathological’. Sometimes there are more: three or four (six would be too complicated). Thus various walking distances may end up being distributed between something like ‘normal’, ‘acceptable’, ‘slightly disturbed’ and ‘seriously troubled.’

In the clinical interview the complexities of a person’s daily experiences with pain are transformed into a metricated value, the ‘pain free walking distance’. This value is written in the patient’s file (and may be counted with at a later stage, for instance if the patient’s fate becomes a topic of clinical epidemiological research). And the same number accompanies the patient during his or her trajectory as a vascular patient. Next to the words ‘clinical findings’ (abbreviated to *clin.*) on future forms and letters, an indexed number will appear: *100 m.* or *250 m.* But it may well be that decisions about treatment translate this value into something like ‘severe’ or ‘too short’.

In the outpatient clinic ‘pain free walking distance’ is not the only parameter for assessing the severity of intermittent claudication. Surgeons also consider whether a patient’s condition is *life-style limiting*. Finding an answer to this question takes them beyond metrication to a group of more or less heterogeneous elements. The old man who lives in a home and still makes it to his cigar shop is not necessarily limited all that much even if his legs start to hurt after eighty meters.⁶ While that spry woman who talks in such a lively way about Brussels, Rome, her old friends and the grandchildren she likes to visit, is hampered a lot even if her pain only starts after a hundred and fifty meters. For her life-style includes – included – travelling and with all this pain she’s severely limited in that.

Another patient in an interview: “So, yes, sometimes you’ve got to climb the scaffolding. And if, so to speak, you’ve got to go up ten, twelve meters, then I couldn’t get there. And then, if you were up there, if you had to use some strength, then it became too much. Sometimes. And I couldn’t walk well. We always had to walk a lot, and then I took a bicycle, but in the end that was no longer a solution either, for if there was wind and strength was required, I had none.”

While pain free walking distance is a numerical variable based on a single measurement, life style limitation is composite. The elements fused together in composing it are interdependent, but in a non-linear way. Together they form what our surgeon informants take to be a possible reason for operating even if there is no immediate risk of developing gangrene. They work on the assumption that measurements of bodily characteristics aren’t enough to decide whether or not to operate.

Vascular surgeon in an interview: “A short walking distance. Bad pressures, a bad angiography. Fine, fine, but I can’t operate on such data alone. You see: there’s always a risk, especially with these patients, they have bad arteries, after all. Bad cardiac vessels too, more likely than not. So they may not survive the operation. Can I make someone run a risk like that? Not if they have

nothing to gain. So if they're not bothered, if they're fine, however bad their vessels are, I'm not going to operate on them"

Life style limitations: when are they bad enough to make the risk worthwhile? This is a complex cultural assessment. Which, in the clinic, tends to result in the end in a binary conclusion: a patient's condition is life style limiting – or it is not. This then becomes a transportable fact again. While scaffolding, cigars, Rome and the grandchildren do not fit into most forms or files, the verdict *life style limiting* in which they may come be included does. Life style limiting – or not.

So there are various ways of taming the complexities of living-as-a-patient in such a way that a manageable assessment of the patient's condition is generated.⁷ By presenting just two of these, *pain free walking distance* and the notion of *life style limiting* we can see that one simplification is not quite like the other. One gives a value that may be plotted on a graph and counted. A number that may be validated by walking in the corridor together with the patient. The other is a composed cultural assessment. It assumes that numbers alone are empty: their true value depends on a specific person's particular circumstances.

So instead of deploring the way in which medicine reduces patients' lived reality, while having little alternative in practice but accepting the truth of medical facts and the efficacy of its techniques, social scientists and other analysts might consider doing something different.⁸ They might ask *how* a patient's condition is turned into a problem which medicine takes itself to be capable of handling. Or how a patient's condition is turned into a problem-to-deal-with at *any particular site* or situation.

For within medicine a patient's situation can be understood in various ways. And it is important to point at this variety, which tends to disappear in the format of the clinical verdict. A verdict that, in the end, says of patients with intermittent claudication that they are amenable to treatment. Or not.

Which problem is treated?

For patients with intermittent claudication, whose walking distances are too short and/or whose life style is limited, various kinds of treatment are possible. Here I will compare two of these: walking therapy and operation. But what do they intervene *in*?

Operations intervene in arteries. The story goes that the pain that occurs when one is walking is a *symptom*, a surfacing sign of something that is *deeper* and lies hidden in the body; a stenosis or an occlusion in the arteries that are meant to bring blood carrying oxygen from the heart to the tissues. If there is not enough room for this blood to flow, if it faces too much resistance, not

enough reaches the lower legs and feet. Blood pressure there falls. The muscles do not get enough oxygen to work. So what surgeons do is make room for the blood to flow again. They may scrape the debris that encloses the vessel lumen away or make a bypass around the bad spot with a vein or an artificial tube.

Patient in an interview: “Look, human beings have quite a lot of veins which they don’t need. Quite a lot. They can be taken out of the arms as well, so to speak. In my case they took one out of the right leg. And the surgeon inserted it in the left leg, around the sick artery, you see. The sick bit isn’t taken out, it stays right there, and the good bit is inserted next to it, here, down here. Good. And then it’s all neatly sowed up again and a bandage is put round your leg.”⁹

This is an intervention in how the blood flows to the lower leg and the foot that hurt so much before. The *aim* is to allow the patient to walk again afterwards.

A patient: “You almost immediately notice the result, for your leg gets warm again, you see. Before, and that’s a common characteristic of these things, before you had a cold leg. It becomes warm again as soon as the insertions are made. And if there are no complications, you’re allowed to get up again. Carefully at first. And then you’re allowed to go home and they give you the message: walk, walk as much as you can. That’s not easy, it takes a while. But those wounds heal pretty fast, after ten days the stitches are taken out. So you get the message ‘don’t smoke’ and ‘walk’. And all in all it takes about a month before you’re reasonably well again.”

While patients are encouraged to walk after their operation, walking therapy also encourages them to walk – but without operating on the arteries first. Arteries may still be mentioned in stories that help to *explain* to people what is happening in their bodies.

Hospital G. A small consultation room. The trainer takes a picture of the vascular system out of a drawer. He shows it to the patient. “Here, you’ve got a vessel that is partly blocked here, at this point. Not enough blood is able to pass the obstruction. So when you use your muscles they don’t have enough oxygen. That makes them produce lactic acid, which causes pain. That’s the pain you feel.”

Something is laid on the table: a picture of a vascular system. It is used to explain walking therapy. There is an obstruction in your arteries. *That* is why it hurts when you walk. But then again: walking therapy is not going to take this obstruction away. If it were measured now, if an angiography were made on which the vessel lumen were visible, then this would be restricted. And if another angiography were made in a few months time, after the walking treatment, there would be no difference. It would still be restricted.

In studies that assess the results of walking therapy the arteries are not made visible on angiographic images (since angiographies require hospital

admission and are a burden to the patient). Instead the pressure at the ankles is measured, or the blood flow through the calves. Or the oxygen absorption in the (lower) legs is quantified. But often none of these parameters seems to have changed much as a result of walking treatment, even when there is significant *clinical improvement*.

“The clinical improvement was not, however, accompanied by any significant variation in the ankle/arm pressure ratio at rest or after exercise or in the results of the calf blood flow as evaluated by strain-gauge plethysmography. The levels of local oxygen as quantified by TcPO₂ basal values and the TcPO₂ half recovery times, which are today considered a valid index for oxygen delivery and tissue absorption, showed no significant improvement.”

E. Mannarino, e.a. Effects of Physical Training on Peripheral Vascular Disease: A Controlled Study. in: Angiology, The Journal of Vascular Diseases. 1989, Jan, 5-10

Walking therapy does not intervene in vessels. Even if it brings *clinical improvement*, that is, even if a patient's pain free walking distance increases. So what is happening here? The most popular explanation of its mechanism given to patients is that walking therapy widens the *collaterals* of the stenotic artery (that is the smaller adjacent arteries). But if pressures and oxygen absorption do not increase this is unlikely. Some other element in the complex physicalities involved must be being altered. But which? The biochemistry of the muscles, maybe, or pain threshold? So far, the studies I have found in the literature are not conclusive. But whatever the ‘mechanism’, walking therapy does change the pain free walking distance.¹⁰

So there is a *simple* image of disease: it talks about *underlying structures* that may go wrong and the *symptoms which emerge* and follow from this. This image brings dispersed elements together into a single *disease*. The image suggests that intervening in the underlying structure (here the artery) alters the symptoms which emerge (here walking distance). It also suggests that *not* altering the underlying structure means that improvement is impossible. But in practice relations between the various elements linked up with any ‘one’ disease are far more *complex* in character. This suggests that the disease *is not a single object*.

The two interventions being compared here treat different objects: one intervenes ‘directly’ in a patient's ability to walk, while the other intervenes in the arteries in the hope of thereby altering the ability to walk. And while the walking therapist at G explains the patient's pain as a problem *caused* by a blocked artery, this so called ‘cause’ is *not* the problem solved by walking. This is why the internist at G suggests that blocked arteries should not play such a central role in understanding what intermittent claudication is all about. Surgeons currently ask radiologists to make X-ray pictures, angiographies, of severely hampered arteries.

Internist in an interview: “But if you look at their angiographies you see a pipe and it’s clogged up. So the image itself suggests what should be done about it. Go ahead, unplug it. Or insert an extra pipe, if need be. It’s plumber’s work. Oh, sure, they may be good at it, it’s difficult, I respect them for it. But no one would ever invent walking therapy by staring at angiographic pictures”.

The invention of walking therapy depends on letting go of the idea that there is a single disease, arterial disease, situated inside the arteries which emerges in the symptom of pain. Only once the *pain* that occurs after walking is taken as a crucial and independent phenomenon, a *problem* important in its own right, does it become conceivable that training someone to walk further might be a good treatment.

So there also is *complex* image of disease. This does not compose single diseases out of underlying structures and emerging symptoms. But neither does it fragment the various former elements of the disease, its parameters, into ever so many independent beings – as if *more than one* disease necessarily meant *many* diseases. A clogged artery may be linked to pain. But pain sometimes may be treated without opening up the artery. Arterial disease, intermittent claudication, is more than one and less than many.¹¹

An intervention in life

Walking therapy is not an easy treatment. One of the conditions for its success is that the patient manages to turn walking twice daily into a routine. And even for patients who succeed, it takes a while before the results become apparent.

Patient information leaflet of G: “The training implies that for six months you will exercise by walking daily. You can do so at a place you choose for yourself. You walk twice a day for half an hour, the same distance every time. The total distance is divided into sections. After every section you rest for a minute. In the hospital you establish with your trainer how long those sections will be and how often you have to rest for a minute. The length of the sections is such that you can walk without pain. You have to include your twice daily walk in your time schedule”.

If patients manage to include walking therapy in their lives twice daily, the pain in their legs may gradually diminish, or start after they have walked further. But including walking therapy in one’s life doesn’t just increase pain free walking distance. It also changes one’s life.

Trainer in an interview: “The average vascular patient who enters here is a miserable, down-hearted, socially invisible person. They literally don’t follow

what's going on around them any more, they don't keep pace with others. And then after a while, in the course of the training period, you see them crawl out of it. They become active, start to get involved in things again, know how to handle their problems. Often the idea that they can influence their own fate is very motivating for people”.

Walking twice a day is a way of getting out of the house and into the world. People get more outgoing. So walking doesn't only alter a life which is separate from that walking. It becomes part of a new way of living. And this new way of living involves more than walking: it also implies generalised activity.¹²

One might thus come to think that the difference between the two forms of treatment is that, while operations intervene in vessels, walking therapy is an intervention in life. But it is not that easy. For being operated on, in its turn, is not something that only happens to vessels. It is part of a way of living, too. A different way.

Patient in an interview: “For six hours I lay there. Six hours. And by accident I saw above my head, between those wide lamps, the operation lamps, there was something that reflected, and I saw my leg. What they were doing with it. And then you see those colours, the inside, the colours of the inside. And the blood. I saw my blood and what they did with my leg. All that contributed to it, of course. That in the end I felt unwell. I had local anaesthesia. And I fainted.”

Even though surgeons make cuts in a body and not in a life, lying for hours on an operating table is as much a part of life as walking twice a day. Or lying in a hospital bed for a few days and then slowly recovering for a month, at home, afterwards.

In comparing treatments one may ask what these treatments do to a patient's life as if the treatments themselves were external events. But it all gets a lot more complex once one starts to recognise that those treatments themselves are a (more or less prominent) *part* of life. And that they imply a certain *way of living*.¹³

What is it to treat?

Who needs to do something if walking therapies and operations are to work? At first sight this is an easy question: patients take it upon themselves to walk while professionals do the operation.

The trainer in G sits across the desk from a new patient. He first explains where the pain comes from: the arteries that are encroached. Then he lays out the possibilities. A small balloon may be inflated inside the obstructed part of

*the vessel. Or it is possible to make bypass around the bad bit. “And then one may wonder: what can the patient do **himself**? Well, that’s walking. A serious training program. We’ve seen good results with it.”*

Others will blow balloons inside your arteries, others are capable of making a bypass around any obstruction. But walking is something you, the patient, can do *yourself*. Or is it?

Trainer in hospital G: “Well, this former professor of surgery we had, he didn’t believe in walking therapy. For he said to people: walk! And then they came back after a while and they hadn’t improved. But that doesn’t surprise me. There are of course better ways of helping people than just saying ‘walk!’. I find out for them how far they must walk before they had better stop and rest for a bit. And then I have people come back here time and again and reporting back to me how well they are doing. That keeps them going.”

If a professor of surgery tells a patient to walk, this is not necessarily effective. While if a trainer puts a lot of effort into it, walking therapy may work. Someone has to explain to patients that the pain in their legs doesn’t mean that something in their bodies is being destroyed. Someone has to help them work out the number of steps that is best for them, so that they may stop walking just before they start to feel pain and they start to lose their motivation. (Or, alternatively, in other variants of the treatment, to talk about how to keep going even when it hurts.) It is a lot easier for patients to treat *themselves* if someone is able and willing to answer the questions that arise during all those hours of walking.¹⁴

General practitioner: “Yes, surgeons tell patients to stop smoking and to walk. But how? People have trouble finding ways. In medicine it tends to be either, come here, we do it all for you; or: go home and do it yourself. There’s little in-between. Oh, I include myself in this. I don’t know how to do it. There are very few techniques for supporting patients properly.”

Surgeons tell their patients to walk (and to stop smoking) – but to them this is not *part* of the therapy. It is something *in addition to* therapy, a matter of giving advice, providing information. While in walking therapy the talking cannot be separated from the intervention. Talking *is* an intervention.

Angiologist: “The power of this method is in the guidance. Simply taking it seriously. For if a patient cannot figure out how to walk 200 meters, the risk is that they will get laughed at. But stick to taking them seriously. Talk about where they may take their minute’s rest. Have them phone when they want, see them when they need it. It is a lot of work. It’s a lot of work and it is not heroic.”

One of the ironies is that the very people who do all this supportive work also help to hide it. This is no mistake. It even seems part of an effective intervention. For the idea that the results of walking therapy are one's own achievement is itself a boost for a patient's self confidence.

Angiologist: "Sure, the patient expects a pill. A solution from the doctor. It is your problem, doctor, you've got to help me, that's what you're paid for. But no, that's not how it is. That's the nice thing about this treatment, of course. If people improve from walking I tell them: 'You've done that, you've done it yourself'. And indeed they are proud. Very proud. 'Look, what I've achieved'!"

A doctor who simply says 'Walk!' has little effect. While if all the non-heroic work of guiding and supporting is done well, the patient's self-assurance increases from having achieved improvement all alone.¹⁵

This is another complexity in the comparison between the treatments discussed here: that for surgeons talking is external to the *real* intervention, which is a matter of accurate cutting and neatly sewing up again. While in walking therapy the relational work *is* the therapy. But *hiding* this work makes it more effective.

Patients cannot do operations themselves. These are done by professionals and require the collaboration of an extensive medical team. Surgeons, angiologists, radiologists, anaesthetists, technicians, nurses: in order for an operation to work all of these have to co-operate and attune their activities to one another.

In the operation theatre a surgeon and a surgery resident are bent over the right leg of a patient. It is opened up. The skin that a nurse painted yellow with iodine is held aside with a scissors-like instrument. A short piece of artery is visible (to those able to differentiate it from the adjacent muscle and the connective tissue of which it has been loosely separated). The surgeon asks the non-sterile nurse (dressed in green but with no gloves on) for the instrument he needs to prevent the blood from flowing through the large artery that supplies the leg. She takes it out of a drawer, opens the plastic bag, carefully while avoiding touching the instrument. A sterile nurse, with gloves, takes it out and hands it to the doctor. He puts it on the artery, a little above the place where the bypass will be attached. And then he immediately addresses the anaesthetist. "Be careful, Harry, he's got no right leg any more."

The nurses have to attune their movements to the doctor, sometimes on command, but often before any words are spoken. The anaesthetist has to keep blood pressure under control, even when the blood is no longer entering the right leg (the moment that, so far as circulation is concerned, the patient 'has no right leg any more'). The points of contact and the need for mutual adjustment are many. In the middle of all this activity all a patient needs to do

is to be patient. In the operating theatre, well anaesthetised, there is indeed nothing more a patient is capable of doing.¹⁶

But the success of operations doesn't simply depend on the skills and the collaboration of professionals. For in order for an operation to work, patients have to do a lot as well. They have come to the hospital, stay sober, answer questions. And being *patient* is hard work as well.¹⁷

*Patient in an interview: So you have to lie flat. Oh, and first they give you nothing to eat or to drink. And then, for hours you lie there. Somehow everything was aching. My head was behind a screen, but I could **hear** them. And afterwards you're not allowed to move, that may take a while, too. Hours and hours without moving, that's hard. Did you ever do that?'*

Once patients go home again, they are supposed to walk – without a therapist to support them. They must be careful sitting in trains and aeroplanes or other places where they may get immobilised. And it is their duty to refrain from smoking.

Surgeon in consulting room, talking to a patient on her first check up after an operation: "So you still smoke, do you? Well. That's a pity. We'll see you again soon, then. For I'm sure your arteries won't need a lot of time to clog up again, if you can't stop smoking. It's fine with me, I earn my living operating." His voice is low but harsh. Almost ironic.

If a patient doesn't stop smoking, an operation may have worked in the short run but is of little value in the long run. The surgeon doesn't treat this as his own failure or that of the surgical team. Instead he treats it as a failure of the patient who failed to prevent further progress of the disease *after* treatment. Thus, smoking after an operation is seen as a wrong action by a failing patient, which leads to further deterioration and a reason for operating again. In the context of surgery smoking is not a *part* of a patient's problem but its *cause*.

The question of *who* treats is related to the question *what* counts as part of treatment. While the activities of professionals are toned down in the case of walking therapy, when it comes to operations the patient's activities are hidden. In the context of surgery, walking and quitting the habit of smoking are not treatments: they belong to leading a *healthy life*. They are not therapeutic tasks but part of a patient's civic duties. One is to *blame* if one behaves irresponsibly and fails to prevent the recurrence of a disease that the surgical team has so laboriously tackled.¹⁸

Does it work? the studies

The next important question in comparing walking therapy and surgery is how *good* these treatments are. This may be investigated in clinical trials that are published in the research literature.

“The results of our study confirm the importance of physical exercise in the treatment of patients affected by intermittent claudication. Our physical training program did in fact significantly improve the walking capacity of the patients who followed it (group A). An average increase of 87% was registered in the pain-free walking time, while the total walking time was prolonged on average by 67%. On the other hand no noteworthy variations in walking times were observed in the control group B under placebo treatment.”

E. Mannarino, e.a. Effects of Physical Training on Peripheral Vascular Disease: A Controlled Study. in: Angiology, The Journal of Vascular Diseases, Jan. 1989, 5-10

For someone with the necessary skills who spends an afternoon or two in the medical library it is quite easy to find a pile of articles proclaiming the effectiveness of either intervention. Which still leaves open the typical question of a clinical epidemiologist: do these articles report good studies? For clinical epidemiologists tend to search for, and find, methodological flaws even in the published literature. The number of people involved is too low, control groups are inadequate, the statistics are not properly done. Such methodological issues are important: they point to the inferences that have come to be acceptable between what happens at a research site and what may be done analogously elsewhere. They point to the division between what is specific to a site and what may extrapolated from that site as *a valid fact*.

Here, I will not go into all the intricacies of method, but concentrate on only two questions. The first is *what* is being counted in the process of fact production. In the text above walking therapy is being assessed by measuring pain free *walking time*. This slightly differs from the indicator we came across in hospitals Z and G which was pain free *walking distance*. Such small differences may or may not have consequences later on. It is important to pay attention to them. For the outcomes of evaluation studies depend on how the patients' conditions and the treatment's intervention are framed. I have been suggesting that walking therapy and operations have a varied set of characteristics. So which are taken into account and which are not in evaluation studies?

Patient in an interview: ‘The disadvantage of walking therapy is that – well, you have to pause to rest. And if there are shops you can just stand in front of a shop window for a bit. But if you’re somewhere where there’s no reason to stop, people may think ‘Heh, what’s she doing there?’ Like, if you come across someone you know, they may think ‘What’s she up to?’. And I know there’s no reason to be ashamed, but it’s not written on your face that you have bad arteries.’

This inconspicuous but significant experience is kept out of evaluation studies. As too is the suffering implied in lying for hours on an operating table or the fantasies one may have after having accidentally seen one's opened leg in an operation under local anaesthetic. That such *details* are left out is not a matter of bad faith. Researchers may do their utmost to attend to the many elements involved in treatment. Not in concise clinical trials, where only a few parameters of success and failure are taken into account. But in the design of broader evaluation studies, which include monetary *costs*, many research groups also try to explore what they call the *social costs* of interventions. However, quantitative evaluation doesn't make this easy. For all it gives one, in the end, is a balance sheet on which numbers must be filed.

An example. For an operation a hospital stay is required: but how might one take into account *in an account* that some people enjoy being taken care of by nurses for a few days, or to have their family and friends come for a visit, while others just loathe being all of a sudden dependent and part of hospital life?

Researcher: "Sure, we know that it's something to stay in a hospital. We take it into account as best as we can." Question: "How?" "Hmm, what did we do?" Shuffling through papers. "Here I've got it. We've subtracted 6 days from the life expectancy of someone who undergoes an operation, because that is the number of days they spend in the hospital."

This illustrates the difficulty of quantitative evaluation even more clearly than a story in which the effect of treatments on peoples' daily lives is simply forgotten. It is hard to flatten out the many-dimensional complexities of treatments by turning them into numbers. And such difficulties concern not only the intricacies of patients' daily life experiences. The very delineation of physical parameters is not all that easy either.

Surgeon in an interview: "It's always a problem. What have they been measuring if they report impressive successes? The number of patients going out of the hospital alive and with an open artery? The pain-free walking distance a few weeks later? It's rare, in clinical trials of surgery, as yet, that clinical parameters are used. What is more likely to be measured is whether the vessel is still open when evaluated with a duplex after three months, or a year, or something like that."¹⁹

So evaluation studies depend on their initial design when parameters are delineated. Walking therapy, for instance, would never come out of a study as a successful intervention if the degree of lumen encroachment were taken as a parameter of success. Nor if oxygen absorption or ankle blood pressures were measured. It is successful only if the dominant parameter for success is a patient's ability to walk after a number of months of training.

The point of asking the question *what* is being counted, is not to argue

that counting is doomed to do injustice to the complexity of life. This is certain. The point, instead, is: how, and in what ways? What is foregrounded and what turned into unimportant detail? Which changes are made irrelevant and which celebrated as improvements?

Success depends on the parameters of success. Evaluation studies do not show a treatment to be *effective* in a broad, unqualified way. What they may show is a link between an intervention and a few, very specific *effects*. The crucial question, then, is what effects to strive for. This would be easy if patients were always either simply diseased or simply healthy.²⁰ But in *intermittent claudication*, as well as in most other diseases for which patients nowadays visit their doctors, complete cure is out of the question, while there are many possible parameters that may be made to stand in for improvement.

So evaluation studies hinge on the parameters they take into account. But method has many more elements and I want to point to a second one of these here. Like the first, this is not a rule of calculation, and it also arises early in the process.

In order to be able to count, many variables – not just parameters – need to be fixed. Once this is done, they disappear from sight. The *findings* of studies are widely disseminated. They get the attention, are taught, and are embedded in standards, protocols and routine practice. But as this happens the *conditions* under which these findings came into being, disappear. And the fact that these conditions might have been shaped differently only emerges again when they are challenged.

We're in a meeting where a thesis is being defended.²¹ The candidate, a young researcher who is also a trainee surgeon, has gone back into the files of almost two hundred patients in hospital Z who have had an endarterectomy: one (or sometimes two) of their leg arteries has (have) been stripped clean from the inside. He now has to defend his thesis in front of an audience. One of the seven questions comes from a professor from university L, who asks: "Why is it that D found in the seventies in a clinical trial, properly done as far as I can tell, that endarterectomy isn't any good, while you find that it is?" The candidate explains that there may be various reasons. One is that endarterectomy is a difficult operation that is highly surgeon-dependent: if one is very good at it, it works, if one makes small mistakes, it doesn't. In hospital Z it has always been done a lot and there is extensive training and carefully supervision. Another reason has to do with the specific artery in which the endarterectomy is done. The popliteal artery has a lot of curves and stripping it is hard. "But the superficial femoral artery is just like a highway, all straight." In the present study, the results for the popliteal and the femoral artery have been separated. Stripping then proved to be a lot more successful for the second, straighter vessel.²²

The success or failure of an operation may depend on a lot of specificities such as who operates, or on which artery the operation is done. When a study evaluates 'endarterectomy in the leg vessels' it may prove this to be a poor treatment, while separating out 'popliteal' and 'femoral' arteries may show that the same treatment is effective for the latter.

A treatment evaluated is always done under specific – *these*, not *those* – conditions. Which, if are evaluated along with it, become fixed in the process of establishing the treatment. How might they be different, how different might they be?

Fixing variables in order to compare and evaluate treatments is not simply to do with taming the complexities of clinical practice after the event. Engaging in evaluation studies also requires one to *shape* clinical practice, to standardise it. For:

“Rutherford stated that without uniformity in the standards for success and failure of interventional therapy for peripheral vascular disease, the results of different studies cannot adequately be compared”²³

In order to evaluate a treatment, it has to be standardised. Treatment protocols are given or referred to in the studies. This requires clinical practice to be adapted. Take walking therapy: this comes in a variety of forms. It is for instance possible just to say to people they should walk a lot, without further specification. It is also possible to ask people to walk until just before pain it likely to start. This is done in G: preventing actual pain is supposed to help people to stay motivated. Elsewhere, however, pain is supposed to lead the body to change the way it works, and is therefore said to be the crucial factor in training.

The inclination of researchers is to either neglect such differences, going with one possibility, or to treat them as a reason for further comparative research. If walking therapy can be done in different ways, either one is opted for, or the question is asked: which is best? Clinicians have traditionally another way to handle a diversity of possibilities: they may try to adjust the treatment they give to the individual patient who is being treated. This clinical way of working doesn't easily accord with comparative research methods.

Walking therapist in the small hospital of D. “We adapt our training. We make an individual program for every patient. What we think they can handle, with their heart, their motivation, their social life. Some people we ask to walk quite a lot here, on the exercise belt we have here in the clinic. Others can do more by themselves, at home. Overall, it's very impressive. It works very well, even in people who'd been given up on, whose hearts are too bad for an operation. They're sent here as a last resort, and they don't heal, of course, but they improve. Our problem is that we can't prove anything. We've kept all these files, but we don't know how to do it. It's all individualised. We hoped that

you, since you're from the university, that you might help us with that, with how to use our files for publications.”

The creative adaptation of therapies developed by these physical therapists means that the clinical epidemiologists interested in physical therapy (to whom we suggested they should go and talk) will find it difficult to use their files ‘for publications’: to use them as material to show the value of ‘walking therapy’ in general. For how, with all these variations, to phrase what’s *general*? If there are too many variable variables it is difficult to make outcomes transportable from this specific site and situation, this patient, this clinic, to other places, other people, elsewhere.

It is hard to adjust to one another the complexity of good clinical work – directed at individuals – and the ordering devices of good studies – that measure populations. While there is never one, but always a variety of ways to do so.

Does it work? the clinic

There are widely accepted studies that suggest the effectiveness of walking therapy. The angiologist at hospital Z is convinced.

Interviewer: “What do you think about walking therapy?” Angiologist at Z: “Yes, sure, walking therapy. The literature is impressive. It works. If you support people properly it works. But here in Z... There is no support for patients. The physical therapists work within a budget. They are not allowed to do more than their budget allows and they are overbooked already. So it wouldn’t help to just ask them to do it. We all tell people to walk, of course, but it does not happen properly, with the support that makes it work. Just now there’s nobody who can do it.”

The strategy of setting up clinical trials to scrutinise different forms of treatment was based on the idea there are too many treatments, all supported by eager professionals. Not all of these can be good, and surely not all of these can be the best. Thus clinical epidemiology took it upon itself to *rule out* therapies that do not prove to be as good as others. But it doesn’t work the other way round. Studies that show that a therapy *is* effective are not enough for this therapy to come into being. For therapies can only come into being *somewhere*: in a specific site and situation. And if in any site or situation the institutional requirements aren’t in place or easy to put together, if there’s nobody to do it, or just a few people against a set of rules and regulations, then it doesn’t happen. Institutions have a life and a logic of their own. The simple question of who might be paid for taking on a new task, and how, may be sticky and stubborn.²⁴

General practitioner in an interview: “I’d love to propose walking therapy to some of my patients. For I know it works, I’ve seen it does, in G. But if I tell people to walk, or even have them come back regularly, well, it often doesn’t work. I’m not very good at it, I have no time, and a group might also be better, I don’t know. Anyway: it’s no option. None of the physical therapists around here offer walking therapy. They don’t know the first thing about it. And if they did, they would have quite a job getting it off the ground, because as it is, it isn’t covered as a separate activity by most insurance companies.”

For this general practitioner referring patients to a properly supervised walking therapy is no option. The specificities of the Dutch health care system have so far ruled it out.²⁵ So this doctor may explain to her patients all about walking, tell them about the advantages of keeping a note book, of choosing a nice route. But if that is not enough there are no other resources in the town where she works. Walking therapy is offered as a separate treatment only in a few places, such as G where an assistant in the hospital was specially trained to give walking therapy at the time the local angiologist wrote his thesis about it.

So in the clinic, the most urgent question need not be: ‘does it work’. It may as well be: ‘where is it done?’ For a treatment doesn’t spread overnight if a few studies show it is effective. Or cheap. Or a boost to patients’ self confidence. Maybe such arguments in favour of walking therapy would be enough if there were a single *site* where they could be posed. But that is not how the Dutch health care system works. There is no central location from which it is directed. Which is not to say that it is a static system. There are shifts and changes. Since we assembled the material for this study, for instance, properly supported walking therapy has come on a lot of experimental and research agendas. It is even reimbursed. Such developments do not depend on a single directive from a centre, but on a multitude of discussions in a variety of sites. Discussions about costs, financial regulations, professional assignments, indication criteria. And the effects of treatment: again and again. These are discussed long before *and* long after the publication of positive studies.

Patient engaged in walking therapy: “And that doctor, he was so proud. He said to me ‘Tell everyone’.” The patient’s wife adds: “Yes, tell everyone, he said, because when I say that it works, they don’t believe me’. And then I said, ‘Doctor’, I said, ‘he never stops going on about it. How much he’s improved from all his walking.”

If walking therapy works, this is not a self-evident consequence of a technique that has been shown to work. It is something to shout from the rooftops so that everybody hears the news. And it is a reason for pride. Our informants proudly keep on stressing how well it works. Something that doesn’t seem to be all that urgent when it comes to operations.

Operation report. “Total anaesthesia. Cephalotine as a prophylactic antibiotic. Colleague R. starts in median side below the knee with the idea of trying to

elongate the bypass that was still open last week. The bypass proves to be occluded and the popliteal artery and the tibioperoneal trunk unfit for an anastomosis. (...) Tunneling of the varivas prosthesis subcutaneously along the lateral side of the knee and the upper leg. End to end anastomosis with a Propleen 6.0 on to the common femoral artery. When cuffs are loosened a good Doppler signal over the bypass. The foot regains colour well. (...) Post operatively an ankle/arm index measured on the dorsal pedal artery of 1.0.”

The operation report describes what goes well and what doesn't 'on the table'. Here's a successful operation, for even if last week's bypass was occluded a new prosthesis has been successfully inserted. And when the cuffs were finally loosened the crucial indicators pointed in the right direction: there was a good Doppler signal and the foot regained its colour. After the operation the blood pressure in the ankle was as high as that in the arm. Blood flowed again when it didn't properly before.

Vascular surgeon: “But the problem is, of course, that if they have atherosclerosis in one site, usually their whole vascular system is bad. So you operate on their left leg, and then their right leg becomes the limiting factor: that starts to hurt. Or their heart gives problems. And you may tell patients to walk, but when they come back and you talk with them it appears they still don't get all that far. It's sometimes very disappointing for people. They go through all this, a hospital admission, a serious operation, recovery. And then they expect to be cured, but they've got a chronic disease. They're not going to get better. Not really. It's very difficult to explain.”

It is striking. While the proponents of walking therapy try to convince us, their interviewers, that it works, vascular surgeons tend to stress that however much effort they put into operating, in the long run, they have no miracle cure on offer. They say that they keep on telling their patients so. And that they try to tone down their patient's excessive expectations.

Patient talking about his history: “What you think is that you'll go to the hospital and have a new piece inserted. And that that's it. That that's how it normally goes. But in my case that wasn't how it went. And after every new operation I came out of the hospital in a good mood. But the last time I got a fever. And I'm sort of a stress sensitive person. I became homesick. What can I say?”

The institutional strength of the treatment is such that there is room for doubt without immediately undermining the possibility of continuing with it. For while the vascular surgeons of hospital Z do not hesitate to tell us, or their patients, about the limits of operative interventions, they nevertheless still operate. That's what they have on offer. That's what they can do to help the patients who come to see them with, often severe, life-style limiting

intermittent claudication. That's what they're good at, and, even if they voice doubts about it, that is what they get paid for.

Comparing is not simply a matter of producing transportable facts. It is as much a matter of getting walking therapy off the ground. Or of engaging in a difficult relation with operations that help *some* patients, even though this particular patient suffers, expects to be helped, might perhaps be helped, but may also be expecting too much. With some bad luck this patient's situation risks to get worse instead of better.

Comparison situated

Comparing treatments isn't usually done to illustrate the complexities involved. The aims tend to be more directly practical. Thus it may be a result of comparing treatments that one of them is designated as good while the other is outdated. But there are also various possibilities for restricting the use of a specific therapy without ruling it out altogether. Thus, it is possible that endarterectomy is said to be good for one vessel (the superficial femoral artery) and not for another (the popliteal artery). It also often happens that *indication criteria* are explored. These divide patients into groups: walking therapy is *indicated* for one, while others are better off with an operation.

In the current standard for general practitioners in the Netherlands, patients with atherosclerosis in their lower legs are divided into four groups. These are said to be in a different stage of the disease.²⁶ People in stage I have atherosclerotic vessels, but no complaints. This implies that they do not turn up at doctors' surgeries, and will not necessarily be found through screening either. Patients in stage II of the disease come to their doctors with complaints about walking, and they should be treated 'conservatively': the general practitioner must advise them to stop smoking and to regularly go for a daily walk. If a stage II patient's condition is deteriorating rapidly, however, it is wise to refer him or her to a vascular surgeon. And this is also indicated when people have reached stage III (pain that does not go away in rest) or IV (persistent wounds, necrosis). For if patients have reached those stages, they no longer only have an intermittent claudication, but something worse. Their legs are threatened.

(Nederlands Huisartsgenootschap, Perifeer Arterieel Vaatlijden, Huisarts en Wetenschap, 1990, 33, p 440-446)

So this is the proposed division: patients who have the disease to a small extent get unheroic treatment: the advice to stop smoking and start walking. While patients who have the disease to a severe degree are sent to the surgeon for operation.²⁷

This classification doesn't go uncontested. Or, more strongly, dividing patients between these two forms of treatment by means of a system of

classification doesn't go uncontested. The physical therapists of hospital D, for instance, tell about their successes with patients in a bad condition. Some had atherosclerosis too severely for operation (they had problems in various places in their leg arteries and/or their cardiac vessels were in such a poor condition that an operation would be too risky). In hospital D these people are sent for walking therapy as a last resort. Getting to walk often makes a considerable positive difference to them. This experience makes the physical therapists of D suggest that *all* patients with arterial disease should not merely be told to 'get walking', but offered a properly supported walking therapy as a first option. The angiologist in hospital G suggests something similar: instead of dividing patients into two groups on the basis of *indication criteria*, the two therapies should be offered in *sequence*.

Interviewer: "Isn't it strange that there is so little enthusiasm for walking therapy?" Angiologist in hospital G: "Like I said, it's not heroic. And a lot of work. Writing a prescription is much faster: medicine X, 300 milligram, 3 times a day." Interviewer: "Could it also be because it isn't widely known that walking therapy has such good effects?" Angiologist, in a sharp voice: "Look, that is, listen, it's absolutely harmless. You postpone a possible surgical intervention, that is still possible later on. And, well, once you insert a bypass, and it closes off, what's next? Another bypass. And the third one closes off as well. Within a year. And what can you do? Operate again? So there are a lot of arguments for trying walking therapy first. Always. For even if people end up having an operation, at least they'll be used to walking by then."

There are three ways, then, in which *comparable treatments* may come to relate: one of them may win (for any specific vessel) while the other becomes obsolete; they may be distributed over different groups of patients by using indication criteria; or they may be put into a sequence: one treatment is tried first and if it doesn't help then the other is there as a backup.

What is similar in these three instances, is the actor doing the comparing. For, however different the relations between the therapies proposed, the actor who compares them is each time a *professional* – a group of researchers, a set of standard makers, a single clinician, or a team of physical therapists. In present day medical practice yet another actor may be comparing treatments: the patient.

Patient in an interview: "And then this doctor said to me: we could operate on you. We could. But if you want to, you can try to do something yourself, first, you can try to walk. If you walk a lot – it is hard, for really it requires that you walk a lot, he said – you may postpone an operation. It may even no longer be necessary, in the end, if you train properly. And then he said that it was my decision."

This has become a common scene in Western health care: two alternative treatments are laid out before the patient in the consulting room. The doctor

provides what is called *the information* and it is up to the patient to compare them and take a *decision*. How does this situation where an individual patient is being asked to compare treatments using his or her own standards, relate to clinical trials and cost-effectiveness studies, in which professional comparison occurs?

A reception after a thesis defence. This is a good site for field work – or is it discussion? I get to talk with a professor from hospital Z who is very actively involved in research, and I claim: “There is a strange tension between the movement for evidence based medicine and the call for autonomy of the patient. It seems to me as if there are two ways to go about making choices in medicine these days. Either you take it that making good decisions is a professional task and use all the effort, all the science, you can muster to find out what is, according to your standards, the best treatment. Or you do not engage in weighing and evaluating, but turn your data into ‘information’. Thus you shift from a professional mode into a market mode and offer choices to your patients.” Medical professor: “So you think of this as a tension, do you? Hmm. I thought they go together, evidence based medicine and patient choice. We try our best to find evidence, and if we aren’t able to, if our science falls short and we don’t know what’s best, then we shift our problems on to patients. And, very friendly, we say to them that it is their own decision.”

So there is a question: how do professional modes of evaluating treatments and patient choice relate? It is a difficult question that I leave open here, delegating it to further study.²⁸ There are quite some complexities involved.

Patients are assessed when treatments are compared professionally: their pain free walking distance, life style limitations and ankle/arm index are established. They get to fill in questionnaires. Along the way simplifications may be made in one way or another. And yet what comes out of this process is called *information*. Such information is presented as if it couldn’t have been otherwise to patients who are requested, or allowed, to actively assess comparable treatments their turn. They may, or must, decide what they deem to be the *best* treatment. In their own case.

As it is, in the Dutch context, there is often as little choice for doctors as there is for patients. For in most places the question of which is the ‘therapy-of-choice’ is hardly a matter of listing and weighing decisive arguments, but has to do with institutionalisation. So maybe it was a clever move of the Dutch association for patients with arterial disease to not enter into professional discussions about effectiveness, indication criteria or the possible sequential priority of walking treatment. And neither did the association demand that patients should be granted the right to make their own decisions about this treatment. What it did, instead of arguing, was to support a *Working Group Walking* which has produced a video.

“Working Group Walking. The walk video is finished! We are very pleased with the end result and on this occasion we want to thank our 3 actors, members of the Association, for their co-operation. Without their generous help the video could not have been made. At this moment funding is being sought to pay for the distribution of the video. Our final aim is that general practitioners and hospital specialists should give this video to patients with claudication who have to do walking training.”

In: The news vessel. Organ of the Association of Vascular Patients. January 1996, page 5.

Who they are, ‘the patients who *have to do* walking training’ is modestly left open. But there is it: a video to support them in it. The video isn’t going to ask those who look at it every so often how it went over the last few weeks. Whether they could cope, and how they managed to do so. But at least it shows in practical detail, again and again, as often as need be, how to walk. Rest. And walk on again. And it promises that if you keep on trying, then gradually the pain will set in after a longer walking distance.

Complexity

In unravelling what it is *to compare* treatments and patient-conditions I have presented a variety of complexities and simplifications.

- First, there is the simplification that occurs when the intricacies of a patient’s daily life and the problems experienced in and with this life are translated into a form in which it is possible to decide whether (and if so how) it might be amenable to treatment. Instead of following the criticism of the reductionism inherent in this move, I have instead tried to stress that different and co-existing reductions are possible. This means that it is worthwhile asking, locally and each time, what medicine is *making* of a patient’s problems as it opts for one reductive possibility or another. Asking a question of this kind goes against the idea that a disease is a single phenomenon hidden inside the body that surfaces in a variety of signs and symptoms. Instead it gives what used to be called ‘signs’ or ‘symptoms’ a relatively independent existence. They come to stand for various and related problems. A disease no longer remains a single entity.
- But this leads to a second kind of complexity. That of objects (diseases) that are *not one*, but that are *not many* either. For while intermittent claudication is not *really* an encroached vessel lumen inside the body, of which pain when walking surfaces as a symptom, lumen width and pain are not *entirely* independent either. This relation of in/dependence that makes disease/s multiple I propose to call a complex one. It is a relation of more than one and less than many.

- A third kind of complexity came into view when I asked *who* in each treatment is engaged in the activity of *treating*. For in answering this question it became clear that the delineation of ‘the treatment’ isn’t the same in the two cases. In the case of operations the events set apart from the rest of life and called ‘treatment’ include physical action but not talking: talking is merely an external requirement for surgery. Whereas in the case of walking therapy the ‘therapeutic act’ is sometimes taken to be the actual walking, something patients do, and sometimes the supportive work, that encompasses talking, and that is done by professionals. But if what falls under the category of ‘treatment’ is not the same from one treatment to another, this generates an irreducible complexity if these treatments are compared.
- A fourth form of complexity surfaces when one asks which treatment is better. It doesn’t do to ask which of them cures the largest number of patients, for no patients are cured at all. The old dichotomy normal/pathological is not adequate for making sense of what happens to people with chronic diseases. Different treatments may bring each a range of changes with them and it is not immediately obvious which *parameters* to count. The simple question about whether an intervention is *effective* is greatly complexified as soon as it becomes clear that each intervention has a variety of *effects*, some good and some bad, that are difficult to balance.
- A fifth complexity is linked up with the social fact that the very act of *comparing* is not merely an intellectual task but also a part of health care practice. There is an ideal image about health care practices that wants them to alter after the results of a good comparative study are published. But reality is different. Some practices already alter a lot earlier on, in order to make research possible in the first place: they are standardised so as to allow (a methodologically sound and not overcomplicated) comparison. Others do *not* alter even when publications recommend this. Current practice, after all, is often *solidified* in existing materials, skills, routines, desires, institutions and financial regulations. New ways of working may easily fit in with these – or not. And in all this, comparison may itself be an instrument – of stabilisation or of change. Establishing a fact about a treatment may, in any specific site or situation, be inseparable from establishing (or limiting, or continuing) a treatment.
- A sixth complexity relates to the double involvement of patients in the comparison of treatments. On the one hand patients with intermittent claudication are the inhabitants of a diseased body and/or the central node in a life style that is limited. The various possible parameters that may indicate a ‘deterioration’ or ‘improvement’ of their condition, involve different measurements of the patient-as-an-object. On the other hand patients are the clients of health care, which puts them in the position of a patient-subject, a person who may want, or need, to be the actor making a comparison between possible treatments to engage in and/or to undergo.

These various complexities are intellectually challenging. They invite further study and reflection. A lot, indeed, for it is urgent to not just oppose dreams of rationality and order with equally pure dreams of wholistic sensitivity or messyness. It is important to escape from these dichotomies which, in the end, belong together as two sides of a coin.²⁹ As part of that it is intellectually important to not be in awe of, or in deference to, but to *analyse* complexity. Surely the socio-corporeo-technical realm of medicine lacks the magic of mathematics where the complex fractal image appears to be the product of a simple one line equation. But unravelling what at first sight seems too baroque to be true, may allow one to lay it out in linear stories.³⁰ As this text exemplifies.

In health care, however, handling complexities in one way or another is also an, often urgent, practical task. A task that may get squeezed in inbetween others. Or may be dealt with implicitly. If I try to make complexities explicit here, this is not in order to then give a normative advise about how they should be handled in practice – as if I knew. It is, instead, an attempt to open them up – for all involved to attend to. For discussion. Whether this might come to have practical implications or not, depends on whether (some of) those involved in health care may be moved to shift (some of) their questions. From questions that look factual (‘what is the case’) and that require counting, they are invited here to ask questions about values (‘what do we want’) that require pondering about whether, and if so what, to count.

Such a shift, however, can only be for the good if, and as long as, in health care there is indeed a dispersed *we*, who, were it to pay careful attention to all the simplifications it engages in, is likely to come up with better alternatives than those implied in current practice.

Patient information leaflet of hospital G: “In this leaflet the procedure of the training has been described and some information about the calcification and obstruction of blood vessels has been presented. It is of course possible that you still have questions about these matters. Don’t keep worrying about these questions but consult your general practitioner, your physician in hospital G, or your walking therapy trainer. The phone numbers you may want to reach in the hospital are printed in the front cover of this leaflet.”

But who can we phone, you and I, if we still have questions?

*Thanks to the patients and professionals who gave their time and shared their insights with us; Jeannette Pols for gathering so much material and for our discussions about walking therapy; Marc Berg for his work on rationalising medicine; Ant Lettinga for her work on improving treatment; Dick Willems for his unfailing intellectual support; and John Law for taking complexity seriously.

¹ Studying the relation between walking therapy and operations was part of a larger investigation into the diagnosis and treatment of arterial disease that was mostly done in Z alone. At a certain point it struck me that walking therapy was mentioned in the literature, but did not (at that time) exist *as a professionally supported therapy* in Z. This seemed to me an important *absent*. That is why I asked Jeannette Pols in 1995 to go and look for it in other Dutch hospitals. She tracked down its existence in G and went there to study it. She also found patients in various places in the Netherlands willing to be interviewed about their experiences with walking therapy; as well as physical therapists engaged in it in hospital D. We jointly published about this material in Dutch. See: Annemarie Mol and Jeannette Pols 'Ziekte leven: bouwstenen voor een medische sociologie zonder *disease/illness* onderscheid' in: *Kennis en Methode*, 12, 1996-4, p 347-361. An intriguing extra complexity is that while Jeannette was in G, a patient information leaflet about walking therapy had to be written. Jeannette, who had done her field work on a short term research assistant contract with my grant giver, was invited (as someone with writing skills who knew a lot about the therapy and who had some time to spend) to write the leaflet. She did (learning a lot in the process about what, in the hospital, does and doesn't count as 'information'). So if in this text I quote this leaflet, it is with a smile. We (modestly) mingled with our field while investigating it. We plan to still write on this question in A. Mol and J. Pols, 'How to argue for walking therapy?', forthcoming.

² Walking treatment and operations are not the only available treatments for this condition. Another important one is PTA, percutaneous transluminal angioplasty. In this treatment the vessel lumen is widened by inserting a threat into the vessel under X-ray monitoring and blowing a small balloon at the site of a stenosis. I leave PTA out here for the sake of, indeed, simplicity. For the distribution of patients over operations, PTA and conservative treatment in hospital Z, see: Annemarie Mol and Bernard Elsmann, 'Detecting disease and designing treatment. Duplex and the diagnosis of diseased leg vessels' in *Sociology of Health and Illness*, vol. 18, 1996, pp 609-631.

³ Almost all material quoted here is translated from the Dutch. I've taken some liberties in making these translations so as to end up with something that comes close to 'natural' English. The health care situation in which events took place, is also marked by its specific Dutchness. All people who are legally in the Netherlands have easy access to a neighbourhood based general practitioner (for people on low and moderate incomes free once their insurance is paid, which automatically happens when they have a job or live on social security money). Specialists are hospital based and can only be accessed through a referral. This implies that specialist only get to see patients pre-selected for them.

⁴ In the social sciences a lot has been written about differences in pain perception, pain behaviour and the expression of pain between (groups of) people. In its cultural anthropological variants this work has been crucial in breaking down the notion of the natural, given body to replace it, instead, with a notion of the body as a node in the enactment of culture. There are also psychological variants around that differentiate between people who are more and people who are less 'pain prone', thereby turning the sensitivity to pain into a potentially pathological condition. For some examples of an anthropology of pain, see: Marie-Jo Del Vecchio Good et.al. eds. *Pain as a human experience: Anthropological Perspectives*, Berkeley, University of California Press, 1991. For a sociological study of (chronic) pain as a separate medical problem in its own right, in which various connections between physiological and psychological theories about pain are analysed, see: Isabelle Baszanger, *Douleur et médecine, la fin d'un oubli*, Paris, Seuil, 1995.

⁵ In the sociology of science and technology a lot of work has been done to show how generating numbers locally in such a way that they are comparable from one site to the other, depends on large networks in which standards, techniques, objects and references are shared and may be transported. In measuring we, are, as Bruno Latour calls is 'tied in by a few metrological chains'. See: Bruno Latour, *Science in Action. How to follow scientists and engineers through society*, Milton Keynes, Open University Press, 1987. For medicine, however, it is questionable whether travel depends on the transport of a metrological chain, with all the technology involved. This may well be the case for numerical measurement, but the transportation of other elements of clinical diagnosis (such as assessing 'palour' or 'sickness') may well be a slightly different, *fluid* matter. See for this claim, illustrated with the example of diagnosing anemia in villages in Africa: Annemarie Mol and John Law, 'Regions, Networks and Fluids. The Social Topology of Anemia' in: *Social Studies of Science*, 1994, 641-671

⁶ It is intriguing: patients with vascular disease are warned against smoking, it deteriorates their condition. And yet the example of the cigar shop as a likely, attractive goal of an elderly man's walks, comes out of an interview with a doctor. Many doctors have learned to appreciate what is important to their patients' daily lives and when talking in that register they may 'forget' their other norms and be surprisingly non-moralistic. In medical sociology the moralising effects of medicine have attracted so much critical attention, that non-, un- or anti-moralising, as well as handling the interferences between various norms, are understudied. For a good framework for engaging in such studies, see: Nicolas Dodier, *L'Expertise médicale. Essai de sociologie sur l'exercice du jugement*, Paris, Métailié, 1993.

⁷ Note here, that I do not focuss on the *process* by which the problems with which patients enter a hospital are turned into problems amendable for treatment. Marc Berg has given a convincing (re-)description of that process as one that is far more messy (or, one might say, more complex) as its rationalist reconstructions (in simplificatory mode) want it to be. The tale I tell here, however, focusses on *content* instead of process. It tries to articulate some possible outcomes of the work-up of vascular patients and how these 'simplify' the complex problem patients have when they enter the hospital. These outcomes show a specific, analysable pattern, however clean or messy the process of reaching there may be. See: Marc Berg, *Rationalizing Medical Work. Decision-support Techniques and Medical Practices*, Cambridge Mass. The MIT Press, 1997.

⁸ 'Deploring the way medicine reduces its patients' lived reality' is widely practiced in the social sciences as well as in the philosophy of medicine since the early seventies (see for a recent overview and integration: B. Good, *Medicine, rationality and experience* Cambridge University Press, 1994) This has served the function of counterbalancing too high regards for what medicine is able to do, but seems to have outlived itself. Even in as far as it is true, repeating the message has lost a lot of its productivity. For the intriguing suggestion that patients, in their turn, may use their 'objectification' by medicine in the process of establishing themselves as subjects, see: Charis Cussins, 'Ontological Choreography: Agency for Women Patients in an Infertility Clinic' in: Marc Berg and Annemarie Mol, *Differences in Medicine. Unravelling Practices, Techniques and Bodies*, Durham, Duke University Press, 1998, p 166-201.

⁹ The differentiation between *arteries* (that bring blood from heart to periphery) and *veins* (through which the blood flows back again) is crucial to understanding what happens here. Some veins may be missed and thus used as bypass material. The encroachment of arteries is the problem treated in operations. Veins may cause problems as well, not because they encroach, but because sometimes their valves no longer function so that the blood has trouble flowing back to the heart again. This is the problem called varicose veins. Once one is literate in this domain, it is striking that most people are not. I encounter this when presenting talks to academic colleagues in the social sciences and philosophy. Many patients we interviewed say that they encounter this when trying to explain their problems to friends and relatives. And we also interviewed patients who were operated but had not been taught the language that comes with that extensively enough for their story about it to make sense, even to themselves. For a recent collection of essays about questions related to interpreting the body, see: Sarah Nettleton and Jonathan Watson, *The Body in Everyday Life*, London, Routledge, 1998.

¹⁰ The extent to which it does so, varies between one study and another. Comparing the outcomes of different studies is made difficult by the fact that some give an average improvement (of, say, 60% or 80% walking distance, or time), while others set a norm for what

is to be called 'improvement' and then say that, say, 60% or 80% of their patients are 'significantly improved'. For the disorder implied in ordering devices, such as outcome studies or, his case, the protocols that allow for them, see: Marc Berg, 'Order(s) and Disorder(s): of Protocols and Medical Practices', in: Marc Berg and Annemarie Mol, *Differences in Medicine. Unravelling Practices, Techniques and Bodies*, Durham, Duke University Press, 1998.

¹¹ This place between the single and the plural has been described before. See for this: Donna Haraway, (e.g.) and Marilyn Strathern, *Partial Connections ...*

¹² For an analysis of the way a patient's subjectivity may be shaped during his or her daily dealings with a hampering body and bothersome or supportive material surroundings, see: Ingunn Moser and John Law, 'Good passages, bad passages', in: John Law and John Hassard, *Actor Network Theory and After*, Blackwell, 1999, p. 196-219

¹³ Thus the effects of treatments on daily lives is not simply that they 'normalise' it (as some earlier critiques of medicine assumed). They may, instead, differ strikingly from one treatment to another. Compare also the way diabetes treatment has entirely different effects on the lives of the people concerned depending on the standard for 'normal glucose level' that they come to strive after. See for this: Annemarie Mol, 'Lived reality and the multiplicity of norms: a critical tribute to George Canguilhem.' in: *Economy and Society*, vol 27, 1998, 274-284.

¹⁴ The professional as a back-up resource for when things don't go too smoothly, also turns up in other self-treatment programs. E.g. in diabetes care there is often the possibility of calling a diabetes nurse or doctor at all hours in cases of doubt or crisis. In other sites and situations patient-support-groups may have taken such a task upon themselves. Cf. Vololona Rabearisoa and Michel Callon, (paris paper)

¹⁵ Walking therapy may look old, but while people have of course walked for ever, walking as a therapy for those whose legs hurt upon walking is rather new. There are research articles with positive results from the sixties onwards, but currently these are received better, which may well be related to a more widespread trend in medicine to shift responsibilities, not only for diagnosis, but for treatment as well, to patients. See for the professional/lay divides implicated, with the example of asthma, D. Willems, "Susan's Breathlessness. The Construction of Professionals and Laypersons" in: Jens Lachmund and Gunnar Stollberg, *The Social Construction of Illness*, Stuttgart, Franz Steiner Verlag, 1992.

¹⁶ For an excellent description of an operation, that, in surgical mode, focusses on the bodies of the operating team, describing them as if their co-operation turned them in a single body, see: Stefan Hirschauer, 'The manufacture of bodies in surgery' in: *Social Studies of Science*, 21, 1991, 217-319. The collaborations required, however, do not exclude tensions to be played out simultaneously. See for an analysis of the tensions between anesthetists, who must take care of the patient's fitness, and surgeons, who make a patient's condition worse in order to make it better, Nicolas Fox, 'Anesthetists, the discourse on patient fitness and the organization of surgery', in: *Sociology of Health and Illness*, 1994, 16, p 1-18.

¹⁷ It has been argued earlier and more extensively that, not just in specific diseases, but in *all* of modern medicine an impressive if hidden part of the work is done by patients. See: Anselm Strauss e.a. *Social Organization of Medical Work*, Chicago University Press, 1985.

¹⁸ Here, then, surfaces the classical tension between framing people as responsible citizens (who behave rationally or irrationally, properly or improperly, responsibly or irresponsibly) and framing people as fragile bio-psycho-social systems (who happen to be normal or disturbed, capable or incapable, together or broken apart). This tension has been mostly analysed in the context of criminal justice (where disease categories are a way of escaping legal logic) and in the context of psychiatry (where, alternatively, civic rights are a way of escaping pathological logic). For the classical analysis, pointing at the tensions as well as the analogies between 'irresponsibility' and 'insanity', see: Michel Foucault, *Surveiller et punir. Naissance de la Prison*, Paris, Éditions Gallimard, 1975.

¹⁹ In this quote *clinical* stands for the daily life effects of a treatment such as it is reported by the patient and detectable in a physical examination. It is opposed to the outcomes of other, technological, diagnostic techniques. Interestingly enough, in the context of technology development these very diagnostic techniques are called *clinical* in their turn, because they are actually used in the hospital, in opposition, this time, to techniques that are only relevant in research settings. See for this tension also: Stanley J. Reiser and Michael Anbar eds., *The Machine at the Bedside. Strategies for using technology in patient care*, Cambridge University Press, 1984.

²⁰ It has been argued that a clear separation between the two states ‘normal’ and ‘pathological’ was present in classical infectious diseases and that not only the clinical trial but the entire hospital organisation is still modelled as if medicine was meant to cure infections (as it was when these institutions were shaped). A lot of present day problems, then, would arise from the friction between the infection-countering organisation structure of health care and the fact that most present day hospital patients have, in one way or another, chronic diseases. See for this: Jean-Louis Funck-Brentano, *Le Grand Chambardement de la Médecine*, Paris, Éditions Odile Jacob, 1990.

²¹ Frank van der Heijden, *Semi-closed endarterectomy of the superficial femoral artery*, Thesis. Utrecht, 1994. And see: F.H.W.M. van der Heijden e.a. ‘Endarterectomy of the Superficial Femoral Artery: a Procedure Worth Reconsidering’, in: *European Journal of Vascular Surgery*, 1992, 6, 651-658.

²² After the mentioned, and other, earlier clinical trials, endarterectomy was abandoned in most hospitals. It was cast aside as ‘out of date’. Had this been done rigorously, then the study reported here would never have been possible. But in Z, as is (or used to be?) often the case, the former professor of vascular surgery happened to fiercely believe in endarterectomies (not just because believed that they work, but also because they have fewer disadvantages and are cheaper than bypass operations). So he kept the technique alive and taught it to those working with him. For the defence of this thesis that retrospectively investigates the department’s patients, he has come all the way from Greece (where he was born and where he went back to after his retirement). He was visibly moved and pleased to be turned (by the numbers) from an undisciplined maverick into a courageous and creative doctor.

²³ Frank van der Heyden, o.c. 1994, p 9.

²⁴ The specificities of such stickiness and stubbornness differ of course depending on the intricacies of health care organisation and financing. The likelihood of change depends on such things as to what extent it is possible to influence organisation and financing simultaneously; to what extent the costs that will be saved when an operation isn’t necessary are a possible push behind the institutionalisation of walking therapy; and to whether centers of calculation where such balancing takes place exist or are simply lacking. For the booming field of ‘organisation and management of health care’ it is important to take into account the fact that medical facts are not external to, but part of, and dependent on, the organisation of health care. For the argument that this follows from a historical shift, since knowledge production is being inserted more and more in the institutions that use the knowledge, see: M. Gibbons e.a. *The new production of knowledge. The dynamics of science and research in contemporary societies*, London, Sage, 1994.

²⁵ Early 1998 walking therapy came to be included among the physical therapy treatments that, in the Netherlands, are financed with health insurance money. But, as the informant who told me this at the end of that year, added: ‘Nobody seems to know yet’.

²⁶ In mobilising the term *stage* the disease is given a historical dimension. It is taken to involve a gradually progressing deterioration of the condition of a person’s vessel wall (even if this isn’t what happens in every patient, for someone may ‘never reach stage 3’). Talking about stages is part of the language of internal medicine rather than of that of surgery (which tends to concentrate on current structure or performance). For a more extensive analysis of such differences in the case of atherosclerosis, see: Annemarie Mol, *The body multiple. Ontology in medical practice*, Durham, Duke University Press, forthcoming.

²⁷ The standard shows what is the quintessence of the organisation of the Dutch health care system: that general practitioners are to treat ‘light’ cases, while sending in more difficult or rarer problems to hospitals for specialist care. Meanwhile, however, the texts produced by the surgeons of hospital Z also begin by mentioning that people who have a ‘stable intermittent claudication’ are not to be operated on, but to be treated ‘conservatively’. Despite the fact that they *should not* the surgeons obviously still get to see such patients. Despite the fact that they *should not* surgeons also sometimes give patients with only intermittent claudication an operative treatment – and the question how to draw a boundary between the cases in which there are ‘good reasons’ for this and the cases in which there are not, is among the *objects* of this study. It is also a shifting boundary: in 1998, when I’m writing this text, a clinical trial investigating the effects of various walking treatment programs for patients with intermittent claudication is being pulled of the ground in Z.

²⁸ See e.g. Annemarie Mol and Bernard Elsman ‘Incisions and decisions: who acts in surgery?’ in progress. See also the work on surgeons and decisions of Tiago Morera, in progress.

²⁹ It is not just that 'order' and 'messyness' are opposing but interdependent ideals. It is also the case that practically neither of these states can exist in a purified form: they each depend on their other. See for this argument: John Law and Annemarie Mol, 'On metrics and fluids: notes on otherness' in: *Organized worlds*. Robert Chia, ed., London, Routledge, 1998.

³⁰ For the association between the complex and the baroque, see Chunglin Kwa, this volume.