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Would you want to be treated with or by a protocol?

Introduction: doctors are suspicious of their creative colleagues.

The story of Dr Barry Marshall is a lovely example of creativity in medicine. In 1979, he was a gastro-enterologist in Perth, Australia. Working with a pathologist, he discovered a bacteria in the stomach of patients suffering from gastritis or ulcers. You know what followed; Dr Marshall was the first to show that peptic ulcer is an infectious disease caused by the bacterium which he discovered and which was subsequently named Helicobacter pylori. He was nominated for the Nobel Prize for Medicine in 2005.

You could say that he had been very creative. In fact, before Marshall, the teaching was that ulcers were caused by acid and by stress. The whole medical fraternity was convinced that it couldn't possibly be anything to do with an infectious disease, with an apparently indisputable argument: the American Palmer had established in 1954 that no bacteria could survive in an environment as acid as the stomach. The pH of the stomach is about 1.5: in other words very acid, even more acid than German beer (whose pH is around 4).

To imagine that Helicobacter pylori could live and thrive in the stomach, he had to have a particularly creative and open mind. Besides, 'pylore' means 'opening' in Greek.

But Dr Marshall was creative in another sense as well: the sterility of the stomach being considered as an irrefutable fact, gastro-enterologists from all over the world refused to believe in Marshall's research. They mocked him. And so, he decided to impress them by doing some spectacular research on himself: in 1984, he cultured some Helicobacter in his laboratory, and he ingested it! Three days later, he was suffering from gastritis. Preferring not to end up with an ulcer, he took antibiotics, and cured himself. Did this creativity in research convince his colleagues? Still not: the following year, the *New England Journal of Medicine* refused to publish a research article by Marshall on 100 patients with ulcers cured by antibiotics.

Only 10 years later, in 1995, would we start, in France, to treat ulcers with antibiotics. Doctors therefore lost many years…and patients many stomachs, since the treatment of stomach ulcer at the time was commonly gastrectomy. Why was all that time wasted? In my opinion, because Marshall did not go far enough in his creativity.

What then could he have done? He attended international gastro-enterology meetings. He could very easily have discretely poured a few drops of a culture of Helicobacter into the jugs of fruit juice being served to his colleagues during drinks at the start of the conference. Most of them would have developed gastritis on the third day of the conference. They would probably have been delighted: suddenly wiser, they would have congratulated Marshall, they would have thanked him warmly, and they would have believed him.

When Marshall was given the Nobel Prize, he was asked why, in his opinion, his research went unrecognised for 15 years or so. He replied that in medicine, on the one hand no-one is interested in researchers from a small town like Perth, and on the other hand the research prizes are given to those who are working as part of a research team, rather than to doctors who have original ideas. And yet, in 1995 evidence based medicine was already in fashion.

This story illustrates that creativity in care, consisting of going off the beaten track, is essential to ensure good quality medicine. We can also see, sadly, that this creativity struggles to obtain rightful recognition.

Have things improved since Dr Marshall's era? I fear not: certain original ideas continue to be rejected, even if they are based on solid evidence. For example, a few years ago, casualty doctors wondered if they were justified in administrating antibiotics to superficial wounds arriving in the department with dirty or obviously infected wounds. In their department, if a wound was dirty, they did as do all emergency departments: they prescribed antibiotics to the patient, sent him home and reviewed him in clinic a few days later. Usually they found that the wound had healed, and rarely was there an infection. They deduced that the antibiotics which had been prescribed were justified, and even that they were probably not prescribing enough antibiotics. But there was no proof. Anyway, how to show that they were right? They would have had to:

- randomise the patients
- only give antibiotics to half of them
- subsequently compare the frequency of infection in those treated with antibiotics to that of those treated with placebo.

No-one dared to launch such a study. The researcher suggesting it would have been considered unwise by his colleagues, a bit like a military doctor proposing a study to look at the presumed protective effect of a parachute in soldiers jumping out of an airborne aeroplane. In effect, the parachute for the paratrooper is like antibiotics for dirty wounds: until now we have absolutely no scientific proof that they work. No researcher has yet suggested:

- randomising two equal groups of soldiers
- giving parachutes to one of the groups
- making both groups jump out of an air-borne aircraft
- then seeing if there is a statistical difference in mortality between the two groups

In order to evaluate the effectiveness of antibiotics – or that of the parachute – they needed to dare to be a bit creative. An astute team of emergency doctors arrived at a solution;

- They swabbed all wounds as soon as the patient arrived in the Emergency department. This didn't permit them to know the organism or its antibiotic sensitivities straight away: they would only know the results a few days later, when the patient came back to clinic.
- They gave antibiotics right from the first day to all patients with contaminated wounds arriving in casualty, as per usual practice.
- They were therefore able, a few days later, to separate the patients into two groups; those where the wounds were contaminated with an organism which was later found to be sensitive to the antibiotic prescribed, and those where the organism turned out to be resistant. In other words, in the first group, one could presume that the antibiotic had played a role; in the second group the antibiotic would have definitely had no effect.
- They found that infection was statistically as frequent, or more exactly, as rare in the two groups.
- The experiment therefore demonstrated the futility of routinely prescribing an antibiotic, initially and blindly, when treating a contaminated wound.

In spite of that demonstration based on astute methodology, the habit of prescribing antibiotics has not to date diminished in casualty departments. This calls to mind the 15 years, during which gastro-enterologists refused to believe that peptic ulcer was an infectious disease: researchers who demonstrate evidence of creativity seem no more able to convince their colleagues today than they were in 1979.

And yet, the converse is also true: in medicine creativity is encouraged.

It is a paradox: at the same time that creativity is struggling to modify traditional thinking and usual practice amongst doctors, they experience a strong attraction to novelty. In effect, doctors are well aware that the efficacy of the care they provide has its limits. Even though every year brings new medicines and better instruments, the sick continue to suffer and to die. Doctors always want to do better. They therefore have a marked tendency to believe in the value of new things, even if they are suspicious of some of them, as we

have just seen… Doctors are no doubt like the rest of the world: creativity seduces them except when it disturbs them, exactly the same as here at Woltersdorf, the average holiday-maker faced with the denuding exigencies of fashion.

The same state of mind imbues the patients: in general they wish to benefit from the latest discoveries in medical research. They readily believe that the more modern a treatment, the more effective and therefore the more to be desired. More effective, that is generally true. More desirable, that is an uncertain wager, since it requires the hindsight provided by the passage of several decades if not several generations, to uncover the downsides of any new medical innovation.

It is true that this belief in anything new –both the belief of the doctor and that of the patient- allows the placebo effect to have a powerful influence: creativity in care is in itself a factor causing the treatment to be effective, even if the effect is temporary: '*Hurry up and make us of the new treatments while they are still curative!'* the doctor to King Louis XV was already advising tongue in cheek in the 18th century. He was called Jean-Baptiste Senac de Meilhan (1693-1770). He is known for having been the first to declare that oedema and breathlessness are signs of heart disease.

That mocking statement of Senac de Meilhan is still applicable three centuries later:

- Thus, shortly after the discovery of cortisone by Kendall during the 2nd world war, doctors thought that this hormone was the miracle treatment for a serious illness, previously incurable, rheumatoid arthritis (Philip Hench, 1948). Several years later it has fallen out of favour because of its side-effects.
- When laparoscopic surgery came on the scene, it was used with great enthusiasm to 'gently' do cholecystectomies, ovariectomies etc and even nephrectomies. It was a major advance. It was also used in an intervention which is particularly mundane and low-risk, namely appendicectomy. But nowadays, we are just beginning to see that if we use the laparoscope to do an appendicectomy, the complications are more numerous and sometimes fatal, because of the arterial wounds which don't' occur with classical 'open' surgery.
- Creative people periodically invent new substances capable of absorbing haematoma and getting rid of bruising. A large pharmaceutical company brought to market a substance pentosane, without any evidence of efficacy, but which ticked the boxes both for prescribers and for their patients because of an ingenious commercial idea: they gave this substance the name of 'Hemoclar', which means '*clarifying blood'.* Creativity in naming the product no doubt explains why it is so effective. But nurses also demonstrate their own unique creativity when treating bruising: they use alcohol bandages, and are convinced that these are effective, even though alcohol is no more capable than water of crossing the skin. Currently, the latest creative idea for hastening spontaneous healing of haematomas and bruises is based on 'essential oils' extracted from plants.

Creativity and irrationality

In this last example, the creative idea is verging on irrationality. The research project testing the essential oils did not find its origin in reason, but in a prejudice according to which '*that which is natural is beneficial whereas that which is artificial is harmful'.* In this case, creativity is no longer linked to science but instead to faith. One of my nurses asked me one day to allow her to treat a chronic wound with royal jelly, '*because it is even more effective than honey.'* Sub-text: royal jelly, destined to feed the queen bee, is logically better than honey, which is only the food of the worker bees.

Creativity, which has as its foundation, beliefs which have not been proven experimentally have always occupied an important place in medicine. For example, the apparently logical idea that *tiredness is bad for the body, whereas rest repairs sick organs,* has made doctors very creative when prescribing rest:

- Patients with tuberculosis were required to rest for months at a time stretched out on their chaise longue.
- In early pregnancy, rest was prescribed in threatened miscarriage.
- The same applied at the end of pregnancy to fend off premature labour.

- Patients with acute myocardial infarction were forbidden from getting up in the days following their heart attack or from doing any sport subsequently.
- For a sprained ankle, it was thought a good idea to rest the ligaments by putting the ankle in plaster.
- Doctors signed people off work and prescribed rest for acute and chronic back pain.

All these useless recommendations have disappeared nowadays. We are even in the process of discovering, to our astonishment, that sport can have a demonstrable therapeutic benefit in several cancers.

But in other areas in medicine an irrational imagination – that is to say a creativity which has not been subject to scientific scrutiny - continues to guide individual prescriptions. For example, many doctors think that exposing yourself to cold air predisposes you to the flu, respiratory infections or upper respiratory tract infections, and winter viruses in general. Scientific studies have proven the opposite.

The problem of irrationality when it comes to creativity in care becomes even more of an issue in most of alternative medicine: phytotherapy, homoeopathy, acupuncture, osteopathy, thermalism, hypnosis, magnetism, curative diets, psychotherapy, are suggesting unusual treatments: here, the creativity of the methods, and even more so the concepts underlying the treatments, is huge, since it is not subject to scientific method which limits the excesses of creativity in medicine based on science (the dominant mode of treatment in the west).

Some of our patients are far more convinced by the far-fetched creativity of alternative practitioners than by the results of scientific trials: for example they refuse to believe in the necessity of eating less salt to prevent cardio-vascular disease, telling us '*it is impossible that salt is as dangerous as you are making out, since mankind has always eaten salt.'* But they are prepared to believe that there is benefit in eating capsules of human placenta, and even that it is in their best interests for mothers to eat their own placenta just after they have given birth: it will avert post-natal depression, bring in the milk, and speed up uterine contraction.

There is seemingly nothing that can limit therapeutic creativity.

The same creative idea can be both an advance and dangerous at the same time.

In the field in which I work, nephrology, the story of Kt/V illustrates nicely in one example the need for creativity and its danger.

Haemodialysis consists of purifying the blood of patients whose kidneys are destroyed and therefore incapable of eliminating numerous toxic substances usually excreted in the urine. In order to do it a complicated machine is needed, capable of removing these toxic substances. This 'artificial kidney' was invented in 1943 in a little town, Kampen, which you have been near: during our meeting of Medecine de la Personne in 2013 in Holland, you will no doubt remember that Rutger, Netty and Anita took us to visit Enkhuizen, an old fishing port transformed into a museum. The town of Kampen, where haemodialysis was invented, is another port, very close by. In 1943 at Kampen, each patient was able to have just a few dialysis sessions, no more.

Twenty years later, it finally became possible to repeat dialysis sessions as much as one wanted, which allowed patients on dialysis to live several years. That repetitive dialysis was perfected in Seattle, on the west coast of the US. It was then that a question arose: in order to purify the patient sufficiently, how many sessions of dialysis are required? One a day or one a week? The answer was completely unknown. How long should each session last? 10 hours or 24 hours? No-one knew.

Another 20 years had to pass before the answer was known: in 1985, an American called Gotch showed that in order to keep a patient on dialysis in good health, it was necessary to combine a certain length of dialysis, a certain permeability of the tubing which circulated the blood of the patient, and a certain flow rate of that blood. Gotch perfected a complicated mathematical formula, taking into account these three parameters and a few others. That formula was called the Kt/V. By calculating the Kt/V for each patient, it was finally possible to know if they were correctly purified, or insufficiently purified. It seemed simple: Kt/V had to be at least 1.2.

Gotch was a better mathematician and physician than the average nephrologist. Very creative, he invented for them a precious tool. In order to convey to you the usefulness of that number 1.2 for nephrologists, imagine that for cardiologists, someone had told them one day the optimal blood pressure, which until then had been unknown.

Under these conditions, all nephrologists gave themselves the objective of achieving this famous number of at least 1.2. In order to achieve this number, there were several possible methods: for example, doing dialysis more frequently, doing longer dialysis, or using more permeable tubing, or circulating the blood at a greater flow rate.

In the US, people generally chose to obtain a good Kt/V, equal to at least 1.2, by doing very short dialysis sessions (sometimes 3 and a half hours instead of the usual 8 hours), with quite a high flow rate. In Europe, at that time, the opposite was chosen instead (sessions that lasted about 5 hours). In both cases, it was possible to obtain a satisfactory Kt/V. But the American strategy had an advantage for the economy and for public health: if the dialysis sessions were much shortened it meant they cost less money or more patients could be treated.

It is impossible to easily tell if a patient has been dialysed correctly, whether not enough or too much. The nephrologist can only tell after several years, during which the patient stays stable or his general state deteriorates slowly, his muscular capacity, his nutritional status, his cardiac function etc. it therefore took a good number of years for the American nephrologists to discover that their method was bad: while the objective of a Kt/V of 1.2 had been scrupulously respected, the mortality of patients on dialysis had gone up considerably. The alert was sounded in articles with the explicit title: '*the American tragedy'.*

The mathematical creativity of Gotch had achieved a huge advance: thanks to the calculation of Kt/V, it was finally possible to quantify dialysis in a precise fashion. It was no longer necessary to dialyse 'blind'. But that fine innovation, used without care, had disastrous consequences: creativity in care, at the same time as being an opportunity, also constitutes a risk, in other words a danger for patients.

I could give plenty of other examples of creativity leading to an innovation which is <u>at the same time</u> both an opportunity and a danger;

- *In therapy*
  - Kt/V
  - organ transplantation
  - blood transfusion
  - amphetamines
  - anxiolytics (thalidomide, benzodiazepines)
  - antidepressants
  - anticoagulants
  - prophylactic angioplasty
  - fertility drugs (diethylstilboestrol, combined contraceptives)
  - techniques to medically assist conception
  - antibiotic therapy with problems of resistance or of upsetting the natural microbiotic environment

- *In diagnostic strategies*
  - Incidentalomas discovered fortuitously while imaging the adrenals or lungs
  - Removal of thyroid or prostate for slow-growing cancers
  - Detection of cerebral aneurysms
  - The psychological trauma caused by genetic testing

It isn't so much that creativity constitutes a risk, but the expanded use which occurs following the innovation: during the creative phase, one is aware that one is exploring unknown territory, which induces prudence in the few doctors who are innovating. But subsequently, in the phase where the initial innovation passes into general use, doctors willingly believe that they have at their disposal a proven path to follow without any great danger, and from then on they don't take much in the way of precautions.

What is more, the experience acquired by certain therapists doesn't necessarily benefit others. So, in the dangerous domain of optimising Kt/V, this *'American tragedy'* led American nephrologists to stop doing dialysis sessions which were too short, but a great number of French nephrologists seem not to have learned the lessons of this story.

Success or failure in the field of creativity in care: a few real life examples.

I was trained in nephrology in a university department which was particularly creative: my chief of service, Professor Mion, was the first nephrologist in the world to dialyse with acetate, instead of bicarbonate which had been used until then. This invention, in 1964, has hugely simplified the working of dialysis machines for more than 20 years. Charles Mion only needed to sacrifice seven dogs, no more, to demonstrate definitively that his idea was a good one, and applicable to 10's of thousands of dialysis patients.

It was also my boss Charles Mion who put in place the first home haemodialysis in France, in a patient who was a forest warden. He lived in the mountains, in a village which was often snowed in, at 1630 metres above sea level and 234 kilometres from the hospital. This was 1968. You can imagine the creativity which was necessary to install an artificial kidney so far away and at such a high altitude, and to teach the patient to operate this machine all on his own.

My consultant, Bernard Canaud, who was about the same age as me, invented a new catheter for dialysis. Until then, when one inserted a dialysis line, it became rapidly infected and could only be used for a few days. Bernard Canaud developed a tunnelled line which almost never became infected, could function for several years, and could be inserted by a doctor with no surgical experience. The Canaud catheter is still used all over the world today.

Another doctor in our department had the idea around that time of modifying the alarms of the dialysis machine. He wanted to allow a deaf patient to dialyse himself at home. All the dialysis machines had audible alarms. So he had the idea of replacing them by a vibrator which he fixed on the hand of the patient.

I have never invented anything, myself. And yet, I could almost regard myself as creative for two reasons: firstly I 'amused' myself by measuring the blood pressure in the patients' fistulas, while using different models of blood pump on the dialysis machine. Apparently that hadn't ever been done before. Is it useful? I'm sure the answer is yes, but just at the moment no-one has managed to work out what for…

Secondly, I was unwittingly the cause of a world first, thanks to one of my patients who I looked after for almost 15 years. His renal failure is due to an extremely rare genetic mutation: it is the only case to have been described up until the present day. Clearly, it was a geneticist who made the diagnosis, or rather the discovery, in her laboratory and she was as surprised as I was. And so one can be creative without meaning to be!

In the 70'sand 80's nephrology was a young specialty, and dialysis was just starting: there was a huge amount of creativity in the field and it stemmed from the nephrologists themselves. It was in these hospital departments that new ideas germinated. Nowadays, there are also innovations and improvements, but they occur in industrial laboratories and the researchers are engineers. In the hospitals, dialysis has become a repetitive chore, often considered routine by nephrologists. If you want to stay creative, you have to have other ideas than home dialysis which has vanished because of safety worries. We need to invent something other than a vibrating alarm, since we can no longer fiddle with dialysis machines ourselves: they contain as much electronics as an aeroplane.

What creativity is left to us? As an example, we can still be creative in the way we teach: in the corridor where my office is, I have often designed posters inviting patients to eat without adding salt, encouraging them to do sport, informing them about a vaccination, explaining how a drug works etc.

My nurses have invented a card game, during which the patient, while playing the game, learns which foods they can eat freely and which foods are dangerous for them.

They have also encouraged certain patients to work their muscles during dialysis sessions. In general, patients find that their sessions lasting 4 or 5 hours are interminable and boring. Few read or use a computer. Some chat with their neighbour. Others doze. Most of them watch television. My nurses have added a bit of interest to these 'wasted hours' by installing the means for them to pedal as though they were on a bicycle even though they are lying down and attached to their artificial kidney. The official

objective is to exercise their muscles, to guard against diabetes, vascular disease, heart failure and musculo-skeletal aches and pains. In fact, it is also a form of psychotherapy, a distraction and a sociable activity.

Often, where possible, I used to use that lost time of the dialysis sessions for group teaching: I would explain their illness to the patients, the way the artificial kidney worked, the correct way to take their medicines, the advantages and the risks of renal transplant, etc.

On occasions, the patients are more creative than their nurses and then the managers: in this way, in 2011, my hospital built us a new dialysis unit. Rather than putting numbers on the rooms we tried to be creative: each room was given a pictorial name, as attractive as possible: Galapagos, Tahiti, Bali, Bahamas, Caribbean, etc….these dream names delighted the chief executive, who was very anxious to give his hospital an attractive image. On the day of the opening, he asked one of our long-standing dialysis patients what he thought of this semantic progress. The patient sat up in bed with difficulty and replied: 'Sir, you have no idea what dialysis is like…I think you would have done better to call my room Buchenwald, rather than Tahiti…'

When possible, the nurses also play games with one patient, help another to draw, or install an easel on another patient's bed so that he can paint…

On Saturdays there is less work than on other days. We have succeeded fairly regularly, on Saturday morning, in persuading a patient to sing for his neighbours, and to sing with him.

As for Saturday afternoon, I keep it whenever possible for non-medical discussions with certain patients who wish to talk about themselves and their lives. This isn't wasted time, nor time stolen from the hospital: a patient feels better, and we can guide them better in their illness, when we have discussed with them their childhood, their experiences of the war, their family, their occupation…or talked about literature. To talk about death is more difficult but sometimes we do. We even end up talking in Latin or talking in verse. However, I've never made a huge effort to talk about cooking with the ladies or about football with the men.

Sometimes, on Shrove Tuesday, the nurses and doctors dress up in fancy dress for the whole of the dialysis session. On those days we have been lucky: we have never had to deal with a cardiac arrest.

All this is not enough. Some of my nephrology colleagues have done much better by organising holidays for their dialysis patients. This means transporting the dialysis machines, the nurses, the technicians and a doctor. It is very complicated. At first sight, it might seem less important than making sure that the hospital service is functioning well. In reality, given the huge ordeal that is chronic disease, it is in my opinion more vital to take these patients once or twice to the mountains, than it is to audit each month the results of their blood tests. In spite of being convinced of this, I have never managed to do much more than supervise their blood tests. The restrictions placed on us when organising care makes creativity challenging.

We should also, as do some of my colleagues, create links between GP's and hospital doctors. That mutual sharing of experience is very much in the patients' interests: hospital doctors detect errors made by family doctors and don't tell them. Family doctors discover inadequacies in hospital medicine and don't flag it up. There are a few exceptions, like Pierre Carnoy, who are gifted in the art of bringing people together. In these instances, creativity really takes off, and enjoyment with it. But in order to be effective, we would have to do much more. I didn't manage it.

All the same, I would like to describe a moment, brief and tragic, of modest but essential creativity: a moment where it seemed essential to me that I act against what all the other members of the team wanted to do. Was it really creativity? I think so. Was I right to act in opposition to the others? I am convinced that it was the right thing to do. I expect however that not all of you will approve of what I did.

We are no longer in the field of nephrology, but of resuscitation. I take over the care of a 24 year old lady who is going to die soon: maybe tomorrow, at most in a few weeks. She has just been shot in the 2nd cervical vertebra and in the head. She has a high tetraplegia incompatible with life. We think that she is unconscious. We are so convinced of this that we don't even anaesthetise her when we do a tracheostomy on her, or when we operate on her to remove another bullet which has perforated her stomach.

Most of her cranial nerves are injured. Nothing is reacting, and this in addition to her tetraplegia. It is therefore difficult to know what exactly she can feel. However, I have the impression that she is conscious. In fact, I see her eyes fill with

tears when a nurse plays to her messages from her children who have recorded them on tape, to say to her phrases such as '*Mum, I love you. I am going to tell you what I have done today. Get well quickly, darling mother…'*

In fact, this woman has three children aged 3, 5 and 7. They were in a refuge for battered wives and their children. She had taken refuge there. But her husband found her and tried to kill her. He nearly succeeded. He is in prison.

As for her, she is not in a coma as we thought. She has a locked-in syndrome. In other words she can see, hear, understand and feel, but can neither move nor communicate. Having corrected the diagnosis, I see three things that I must do: give her morphine for her pain, give her anxiolytics to enable her to tolerate the ventilator, and allow her to see her children before she dies. Or to put it more correctly, allow her children to visit their mother, and to understand what is happening, before they lose her. It seems to me essential, and what is more, pressingly urgent, since she is likely to die any day soon.

In our team, most of the others don't share my opinion, or at least don't dare to say anything. All except the nursing officer, but she doesn't realise that we need to act quickly; she would like a psychologist to be present while the three children come to see their mother. That would delay the visit by 5 days. 5 days of additional suffering for the disorientated, unhappy children, and for a mother who weeps. I refuse to allow this delay, so here I am organising the visit on my own.

One of the teachers looking after the children comes to get the latest news. As we have a camera on the unit, I suggest that he takes back to the children a photo of their mother, to help them to understand, as much as possible, that she is in hospital, being looked after, alive and seriously ill. One of my colleagues expresses his disapproval: he has never seen anything like it on the unit. But, thankfully, the teacher thinks, as do I, that the children need to have an explanation and the truth, rather than obfuscation, supposedly to protect them.

I manage to get in touch with the childrens' judge. She understands the situation, approves and immediately authorises the visit. I ask a student nurse to place all around the patient's bed the drawings, the cut-outs and the messages sent to her by the children. Thus, they will be able to see that their mother is getting their messages. Unfortunately, the student nurse puts the childrens' messages where the mother can't see them, since she can't move her head. Even though I have other things to do, here I am, obliged to correct that thoughtless oversight, by bringing in drip stands, between which I hang a string, in order to attach the pictures where the patient can see them.

The children arrive, accompanied by three teachers. It is very emotional. We explain the situation to them. We lift them up. We put the little ones on the bed. They talk to their mother, hug her and stroke her. We are overwhelmed. The older one who is 7 doesn't want to let go of her mother's hand. I explain to her that that hand can't feel anything, and that it is better to touch her cheek. The mother reacts and makes a face. The little girl understands completely. She asks what the tubes, the screens and the machines are for. We are aware of a childish tenderness which is rather joyful, an emotion not usually seen in an intensive care unit.

The visit lasts an hour. It finishes with a tea in the corridor provided by the teachers. Everyone feels both saddened and pleased that this visit has been able to take place. No-one is in any doubt that it was a precious time. We should organise more, if death allows us enough time: surely you have the right to see your mother another one or two times, when you are 3, 5 and 7 years old and immersed in a family drama which will have continuing repercussions.

But there would be no other visits. A member of staff who was on holiday comes back, and restores the situation as she sees it. The morphine and the anxiolytics are stopped. There is only one priority: to transfer that terminally ill woman to another ward. She has to die elsewhere, in order to free up her bed for emergencies which arrive on our unit every day. The three children are forgotten. And yet, that female member of staff also has children, who are the same age. In all the changes which she introduces, I perceive also her desire to make me feel that I should not have tried to interfere with the usual practice on the unit: no question of allowing any creativity!

What motivates creativity.

When we ask ourselves what circumstances favour creativity the most, we can arrive at contradictory conclusions. Here they both are:

- Long ago, I did my endocrinology attachment with a boss who had a good reputation, Jacques Mirouze. This wise man and great teacher seemed to know everything, but he advised us to limit our interest to a particular area. I dared to say to him that I took another view and that I wished to understand the function of the pituitary as well as the adrenals, diabetes as well as acid-base imbalance, nutrition as well as reproduction. Slightly annoyed, he replied; '*As for me, I focus on one thing only, diabetes. If you don't specialise, you will create nothing.'* In 1981, he created the first

implantable insulin pump for use in diabetic patients. In 2002, the team which he put together implanted the first prototype of an artificial pancreas: two world firsts.

- The opposite point of view is illustrated by another great creative mind, Bertrand Piccard. He is a doctor, but it isn't in the medical world that he is currently doing his research: at the moment, he is trying to circumnavigate the world in an aeroplane powered by solar energy by day, and gliding by night. He has just crossed the Pacific, flying for five days without stopping. At the start, in order to design this aeroplane, he consulted the best experts in aeronautical engineering. They all told him it was not possible. Bertrand Piccard therefore asked the advice of wise men who knew virtually nothing about aeroplanes and who, because of their ignorance, agreed to work on this project which experts were sure would end in failure. This ignorance bore fruit, in that these novices imagined solutions other than those thought of by the experts. Here is Bernard Piccard's conclusion: '*An innovation is not an extra new idea, but an old certainty which has been removed (…) Often, creativity and innovation do not arise from within a system, since it is too mired in precedent to be able to invent anything new: it is not the candle-makers who invented the electric light bulb; it is not the car manufacturers who made the best electric car: it is a millionaire who made his fortune on the internet who thought of the Tesla.'*

Elsewhere, Bertrand Piccard has also been very creative in the field of medical care: he designed on his own a plan of action to fight against 'noma', a mutilating infection of the face in children in Africa who are malnourished and who lack washing facilities.

Obstacles to Creativity

As we have previously pointed out, in medicine, each generation feels the need to innovate compared to the previous generation. Creativity exists, and hence new discoveries, innovation, and in principle progress if the innovations are judicious.

Medical creativity in our time has been the source of numerous advances, for example:

- Monoclonal antibodies allow us to treat certain cancers and certain immune diseases.
- MRI allows us to observe organs functioning.
- Robot assisted surgery is less damaging than the surgeon's fingers.
- Gene therapy holds the potential to cure the disease which currently threatens humanity the most; namely, diabetes.

But equally, creativity in our era has introduced two tools which, in my opinion destroy creativity. It is a sort of paradox.

- The first tool which puts obstacles in the way of creativity is the race to improve productivity in care. We must treat more quickly so that the care will cost less. A carer who is obliged to rush stops being a decision-maker who reflects on what they are doing, and becomes a technician who is delivering a treatment.
  Thus, some of my nephrology colleagues hold outpatient appointments which last 20 minutes or so. Mine last an hour, to which I often need to add, before I see the patient, half an hour of study of the patients' thick notes. And after the consultation, ten minutes to decide on the findings, and 20 minutes to draft a letter, even two or three letters. Reflective thinking is almost always necessary, and creativity also is often needed, because the majority of patients who consult me about a renal problem, have other related problems as well: physical problems (diabetes, hypertension, cardiomyopathy, arteriopathy and chronic pain, for example); socio-economic problems (isolation, poor understanding of French, for example); psychological problems (fear of the disease progressing, refusal to adhere to the diet, depression, for example). Even with renal disease, which is in theory simple, every person who consults me is a unique and complex case, which requires management tailored to that individual patient. Every person who comes to see me requires me to be creative. Jean Hamburger, the world inventor of the concept of resuscitation in the 50's, and the founder of French nephrology, was already saying in 1984 in his book '*Power and fragility': 'How can*

the doctor both adopt a personalised psychological approach and deliver technical treatment without leaving anything out? (…) this is so difficult that the task facing the doctor (…) appears to be a form of creation eternally recreated with every new patient.' Jean Hamburger underlines himself the word creation. In a consultation lasting only 20 minutes because of the pressure to be productive, I think it is impossible to be creative.

- The second tool which impedes creativity, is the frenetic drive to have protocols for everything, which we are seeing nowadays.
  Obviously, I am not seeking to criticise the move, seen in all eras of medicine, towards defining well-thought out diagnostic strategies where nothing gets forgotten, and proven medical therapies where we make the least possible mistakes. I am criticising a completely different phenomenon, these pseudo-useful processes which have been appearing at an insane frequency of several per week for several years now. Many of these protocols destined for carers are illegible because of their complexity, unrealistic because of their rigidity, impossible to implement because of the time they waste, discouraging because of their sheer numbers, dangerous because they blunt the doctor's vigilance and not even effective since they apply only to the majority of patients, not to all of them.
  Applying a protocol assumes that all patients resemble each other. Diseases may resemble each other, but not patients. As the Canadian doctor, William Osler said, '*it is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.'*

  I believe that the ossifying protocolisation of medical practice doesn't really translate into a desire to improve medical practice, as is proclaimed. It translates into quite another desire, which we summarise in France under the title of 'defensive medicine' (literally the principle of precaution). This has the appearance of being a good thing: it is about avoiding awful errors such as thalidomide, growth hormone contaminated by prions, transfusions contaminated by the AIDS virus, and the 19,490 deaths caused by the heatwave in France in 2003. All well and good. But on a deeper level, defensive medicine, and the numerous protocols which are its corollary, is the translation of several negative characteristics of the 21st century: fear, refusal to take personal responsibility, suspicion of any original ideas, willingness to assign blame to an individual whenever an undesirable event occurs, the mistaken desire to live life without risk, the illusion that accidents are avoidable, as long as one imposes rules and most especially prohibitions. It kills off creativity and breeds protocols.
  Older nephrologists say nowadays that if protocols had existed 50 years ago, dialysis would never have been invented, nor renal transplant. I would like to quote Jean Hamburger again: '*I remember a colleague (…) saying to me that I had no right to attempt transplant in man before I had completely understood the underlying mechanisms. And yet, it is in this way that medical science makes progress, particularly when we are dealing with fatal disease. The practitioner then has the right to try anything, in this case, the moral high ground consists in daring all.'* Yes, the object of using protocols is to rein in bold gestures and new initiatives. That is then almost the same thing as reining in creativity: we discourage it using intimidation and rules, which find expression in diverse forms: protocols, recommendations, good practice, consensus, guidelines or quality measures.

  Would you want to be treated with a protocol or by a protocol ?

  - To be treated **with** a protocol, means that your doctor uses a care tool with care, knowing for example that a validated treatment, say, anticoagulation, is beneficial for the majority of patients, but harmful for others, and that we need to balance the advantages and the disadvantages.
  - To be treated **by** a protocol, means that your doctor has labelled your illness, say end-stage renal failure, and that he is going to automatically couple that diagnostic label with its corresponding treatment label, say urgent dialysis. This isn't good, let me tell you. But that is what is happening: there is no room for thoughtful reflexion. It is thought that delaying treatment to see things more clearly, or to stabilise the patient, adds nothing. Choosing not to treat is not an option. That false certainty and that useless rushing into treatment make the doctor feel on safe ground. But it

multiplies morbidity and increases the suffering of the patient, which one of my colleagues describes with weary resignation: '*the great God Protocol has struck again…'*

Protocols which constrain us and are prescriptive aim, in principle, to improve care. However, in my opinion, they often make it worse. In medicine, in order to look after a patient, there is no one good method, but several, according to the personality of the patient and that of the doctor.

Personally, I use an anticoagulant which is forbidden in cases of renal failure as much as possible in my dialysis patients. I should use other anticoagulants, those which are officially authorised. They are less dangerous at the point of using them, but they represent a grave risk for the future: their use destroys the patient's' veins. In good conscience, in spite of the regulations, I would not prescribe them to a member of my family. I take pains therefore to be honest and not to prescribe them for my patients. I act outside the law…I have encountered many doctors who told me; *'That protocol, that indication, is poor. I apply it to my patients because I don't have any choice. But if I was looking after a member of my family, I would not use it.'* This is typical of our conformist times, which don't like freedom, responsibility…and therefore creativity at all.

In truth, it often happens that we take decisions when treating our patients which we know are the wrong ones. It is absolutely terrible. Our desire to do good, which is an 'Intrinsic motivator' is anaesthetised by rules which aim to do good as well and are 'extrinsic motivators'. In general, we get better results by allowing intrinsic motivators to influence our behaviour. This analysis has been developed in the field of economics by the Nobel Prize winner in economics Jean Tyrol. I think it is applicable to health-care workers. I have always placed a lot of trust in my nurses, rather than always giving them orders.

Do you watch the American series on television, where in the A/E, the patients always arrive in extreme distress, the young doctors always have inexhaustible energy, and the blond nurses are always searching for love? Each episode shows us a patient whose diagnosis has baffled a battalion of doctors, until one of them finally finds the solution. How does he find it? By intuition, by chance, because of a clue which no-one had noticed. I find it astonishing and contradictory that nowadays we want to have protocols for everything, while the television series are showing the opposite: if all the world thinks in the same way, all the world is blind.

Besides, you are a realist in medicine, you know that unless you do the same thing all the time, you can't do everything perfectly. So, happily for our patients, we are all more or less generalists. Going forwards, our competence limits itself to being good enough in most of our duties, and excellent in only some of them. We succeed in being excellent only in those areas which stimulate our creativity. So, I don't know any dialysis unit which is perfect in every domain: some are excellent in the quality of their fistulae, others in their psychological support, others in dietetics, others in the quality of the water, others in night-time dialysis, others in the setting up of home dialysis, etc. The localised excellence of each centre acts as an example and pulls up the other centres. That excellence doesn't derive from obedience to a detailed protocol, but on the contrary, from a willingness to find a better way of doing things. For the last 50 years, the greatest advances in dialysis have always been born out of local initiatives, related to a particular passion of that team for their preferred field of interest. The generalisation of protocols discourages these individual passions, and blocks progress, quite simply by blocking creativity.

Two years ago, in Holland, Jonathan Pye said to us in his talk 'we should regard care as a form of love'. Will we see a consensus group produce a protocol entitled '*Clinical recommendations to improve the way we show love in caring for our patients, in 24 stages'?* It wouldn't surprise me. Firstly since ethical committees have already started to draw up protocols relating to ethics in care. And then because I discovered that a commission into nursing care drew up and disseminated a protocol, entitled *'The washing of dependent patients, in 24 stages'.*

If we continue in this direction, one day, experts will devise a protocol for medicine of the person. When that day arrives, medicine of the person will cease to exist. For it is a constant call to creativity for the doctor and for the patient.