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When medical care becomes a burden, at what point should we decide that less is more?

My talk has four main areas of emphasis:

1. What are the principles by which we treat patients ?
2. How do I enter into a dialogue with patients and their relatives ?
3. What are the prerequisites for us to treat someone ?
4. How is palliative medicine administered in practice ('less is more !')

As doctors, we have submitted ourselves to the ethical requirement to do good for our patients (beneficence) and to do no harm (non-maleficence). Equal with these are the principle of the patient's autonomy (respect for autonomy) and the fair distribution of the services the health system offers (justice). These 4 principles espoused by Beauchamp and Childress have, since their publication in 1977, been regarded as the classical principles of medical ethics.

The World Medical Association formulates something similar in its declaration of Helsinki (trans. note: ethical principles for medical research involving human subjects): "The doctor should act in the best interests of his patient in practising his medical profession."

So much for the theory. Beauchamp and Childress already point out the conflicts which arise from the equal status of these 4 principles. Do our ideas of what is good for the patient coincide with the patient's own ideas? How often does our 'well intended' ***beneficence*** collide with the patient's autonomy? Which of the two principles is to be given greater value? Every ***beneficence*** by us as doctors runs the risk of unintended consequences. Physical wounds and pain are the consequence of every surgical intervention. Every prescription of a medicine carries the danger of side effects.

As the four principles are of equal status, our medical profession is an independent profession: our decisions on treatment must not be made in a mechanical way according to S3 guidelines [translator's note: these are the European Evidence based guidelines] or by the book; rather, they should be reflected on, with an eye to the future and carefully weighed up (Giovanni Maio). The central achievement of medicine does not lie in practical implementation, however important that implementation might be, but in the deliberation which precedes it, as to whether the usual treatment makes sense in this case, or whether a different one is more appropriate.

My first example: an 82-year-old patient, Herr U., former mathematician, had been on anti-coagulants for permanent atrial fibrillation. As a result of a worsening hemiplegia, he was admitted to the stroke unit at the neurological hospital. Diagnostic imaging showed a cerebral haemorrhage in the region of the basal ganglia. At first the patient was responsive, but in the following days his condition deteriorated and he became comatose. A further scan shows an increase in cerebral bleeding. I am asked for my opinion as a palliative care specialist; neurological colleagues expect no improvement. I am to advise on further treatment and preparation for the patient's discharge. At his bedside, I find his desperate wife. We seek out a quiet space on the ward and sit down. She tells me about the living will her husband wrote out by hand years before and which she had handed a copy of to the ward. Although the passage was marked in it which stated that there was to be no artificial feeding given in the event of irreversible brain damage, neither intravenously nor by nasogastric tube, her husband had had a nasogastric tube inserted and was being fed through it. She was intervening as his legal representative, having lasting power of attorney. His wife had shown the passage to the doctors and nurses treating him. Their reaction was: "Do you want to let your husband starve to death?" She recognises the ethical conflict and cannot resolve it on her own. We discuss together how things should proceed: she would like to take him home with her and, with support, be with him and care for him there till the end of his life. We agree to achieve this objective as quickly as possible and then to consult at home about whether to retain the nasogastric tube. Three days before his discharge, Herr U. pulls the nasogastric tube out with his good right hand. This time his wife insists and refuses permission to insert a new one. Herr U. is taken home without a nasogastric tube and remains there till the end of his life.

As doctors caring for our patients we should help them and their relatives actively to face up to conflicts and also to endure them until the point is reached when external circumstances simplify difficult ethical decisions or sometimes even resolve them on their own! In doing this, we should see the human distress, both of patients and their relatives. We must listen to them, give them time and thereby communicate to them that we are taking them seriously. As clinicians, we are trying to come to a consensus regarding the treatment regime; this does not always meet with agreement by all parties concerned. We should – as an aside – also recognise the difficulties doctors face in their daily clinical routine under pressures of time and cost. In these circumstances doctors act more often according to set rules. They proceed solely within the algorithm of so-called 'objective' data, thereby ignoring the patient's situation, wishes and thoughts (according to G. Maio).

An 82-year-old patient, Herr H. is admitted to our palliative care ward following a fall at home. Up until this event he has lived alone in his flat. We know of a secondary AML (acute myeloid leukaemia) following on from chronic leukaemia diagnosed two years previously. The colleague at the outpatients' department treating him for the past 2 years tells in despair of his stubbornness: every suggested medical treatment is stopped prematurely or refused by him from the outset. I sit down by his bed and we look at each other. I ask him: "What do you think is going to happen to you in the future?" His angry reply is: "See to it that I get my strength back. I want to go back home." – "I can understand that." He looks at me in astonishment. "It's nicest being at home," I say in explaining my answer. "What do you need to be able to go back home?" He thinks, but can't give an answer. "Your illness is incurable," I say attempting to spin out the thread of the conversation. He is aware of this fact, and subsequently we broach the subject of alternatives such as a residential hospice. "Then I'll have to take my TV, I've only just bought it." I'm able to assure him that it'll be possible for him to take his own TV set to the hospice. He allows us to go ahead and try and get him admitted. His admission doesn't take place: all the beds in the hospice are taken, and the waiting list is long. His ambivalence keeps coming through in conversations: on the one hand, he doesn't want to live longer if his weakness prevents him from getting out of bed unaided. On the other hand, he does want to carry on living and have more of the blood transfusions which strengthened him in the past. Herr H. has a transfusion of 2 units of blood. But on this occasion, he doesn't feel stronger as a result. We stop the treatment for his leukaemia and cease all further laboratory tests. Herr H. is greatly preoccupied with the distribution of his estate: he offers us his scooter and mobile phone, which we decline with thanks. Two days before his death he waves me into his room. I'm to go to his cupboard and take out a cloth bag that is in there. In it are two carved figures of animals from Africa which he's often told me about. "You must take them!" is his last instruction to me.

Soren Kierkegard (1813-1855, Danish philosopher, theologian and writer) described most appositely how we can help someone and at the same time pay heed to their wishes and thoughts. I quote: "If we want to help someone, we first have to ascertain where that person is at. That is the secret of care. If we are not able to do this, it is an illusion to think we might be capable of helping another person. Helping someone implies that we understand more than they do, but we must first understand what they understand." End of quote. Kierkegard enjoins us to "find out where the patient is at."

In the New Testament Jesus proceeds in a similar way when healing the sick. In Mark 10 verse 51 he asks the blind Bartimaeus: "What do you want me to do for you?" What sort of question is that? The objective facts of the matter are clear: he's blind! Jesus waits for an answer from the sick man before he acts. Or in John 5, Jesus comes across a paralysed man at the pool of Bethesda. He's had his condition for 38 years. In verse 6 he asks him if he still has hope. When Jesus sees him lying there and learns that he has been sick for so long, he says to him: Do you want to be healed? (John 5.6). Jesus takes his time and takes the whole person seriously before he acts.

I open doctor-patient conversations with questions to my interlocutor: what does he already know about his illness? How does he think things will proceed? (What now follows is a digression about the way doctors should conduct such conversations). I asked Herr H. an open question about his thoughts about his future. I could just as well ask about the past: "Please tell me in detail all you know about your illness and your treatment so far." A ground rule: whenever possible these conversations should take place when seated: on a chair or, if necessary, also at the foot of the bed if the patient gives permission. We should meet the patient at eye level – and all parties are much more relaxed when sitting down. If relatives are there, the patient should be allowed to speak whenever possible, even if the relatives are sometimes better informed. We mustn't interrupt the patient when he's speaking, but reinforce by nodding or using 'Mmh'. Always use questions like: "Please tell me again what you mean by – and I repeat the expression used by the patient --?" As a rule, these patient statements last no longer than 2 minutes. Through them we do not just get to understand the level of his knowledge, but also what is worrying him and how he is dealing with that.

If I am asked by cancer patients for a prognosis, I first ask back what he himself thinks it is. Often you get surprisingly precise estimates. On the other hand, I also know of patients' estimations which lead to unrealistic planning around their illness. If we have to give a prognosis, we never give an exact point in time: by Easter or by Christmas, nor a number: at most 3 more months or 3 years. In the end, we are doctors with a great deal of specialised knowledge but we are not prophets. It's better to use periods of time: in the event of a bad prognosis, for example, a few weeks – or even days, and vice-versa. Such conversations can seem difficult, but they can bring relief to patients. They are finally permitted to speak about their worries and needs. We are patient and listen, and so they feel they are being taken seriously. We know then 'where the patient is at'. This brings about a collaboration; or to use the modern German word '*Compliance*'.

Many patients sense the approaching end of their lives and have the feeling that it is not they or the doctor treating them that have a hold on the illness, but the illness that now has a hold on them. But their 'organ' practitioner continues to think he has another arrow in his quiver to fire at the illness. The organ doctor is on a 'journey of hope'; the palliative care doctor is on the 'journey of reality'. Please don't think that the palliative care doctor is right in every case. I cannot inform every terminal patient about his limited prognosis.

There are not a few patients who want to hold fast to life till the very end and clutch at every straw the doctor holds out to them. Some travel throughout the country until they find a doctor who suits them. Difficulties of a particular kind emerge when hope is revealed as an illusion or, even worse, when the doctor is a bad apple or a charlatan. There's a lot of money to be earned from desperate patients seeking help. I do not wish to say anything further about the stress caused by this type of 'medicine' at life's end.

I try to tell relatives who want to stop me from having a conversation with the patient that I'm only going to answer those questions that are asked, and will not answer questions which are not asked. How often is it then apparent from this that both patient and relatives are very well informed about the illness, but have not dared to have a conversation about it for fear of causing the other distress. We can thus help them, through a discussion which clarifies the position, to spend their last time together openly discussing and planning, instead of in an ever-deepening avoidance of reality.

Frau D. was brought back to Germany from Morocco by her children because of a cholangiocarcinoma [cancer of the bile duct]. In the past, stents had regularly been inserted into the bile ducts. Now colleagues in gastroenterology could see no further possibility of relieving the cholestasis. The patient was accompanied by her son and daughter as her bed was transferred to the palliative care ward. Her face was sunken, her skin dark and leathery; the jaundice was only visible in the whites of her eyes. Her daughter came straight up to me: "You mustn't tell her anything about her condition!" The daughter speaks German pretty much without an accent. She's been married to a German for 18 years. She interprets all the questions for me: whether there are any pains, breathing difficulties, hunger or thirst. The mother smiles a tired smile at every question. No. She's extremely weak and can't get out of bed any more. After the consultation, I take the daughter into my office. "If my mother hears how sick she is, she'll just give up completely. She has suffered from depression in the past," is the reason she gives. I look at her questioningly. What do you talk about with your mother? Has she asked what is now going to happen to her?" – "No. We talk about family in Morocco, about my three boys." – "And the illness?" – "I tell her it's going to get better!". I look at the daughter questioningly. "What are you going to say to your mother when she feels that she's getting worse, and you tell her she's getting better?" A long silence. "Yes, I know … I have to talk to my brother."

I'd now like to come to two basic preconditions for medical treatment: firstly, we need the consent of the informed patient; secondly, there needs to be a medical indication for treatment.

To begin with, consent. The information given must be so much more precise if the planned treatment carries greater risks and is going to be more problematic. Explanations should be in words the patient understands. Diagrams help understanding. The explanation must be honest; if the chances of success are small, these should also be given (for example, third line therapies – chemotherapy for a solid tumour). Only then can a patient decide if he wishes to put up with the unavoidable side effects. Or he turns down the statistical possibility of a slight extension to life in favour of a better quality of life for his remaining days, for there will be none of the side effects of chemotherapy. Thus, we arrive at 'informed consent' with the option of reviewing the decision at a later date.

Refusing chemotherapy does not automatically mean shortening life. In a study by Themel in the USA, patients with advanced lung cancer were studied. All were incurable and had received chemotherapy. The first group of patients received palliative treatment from the start, the second half only according to their needs as the disease progressed. The quality of life of the first group was, of course, better, measured by various scores and by the degree of depression. The astonishing result was that the 50% of patients who started palliative treatment earlier lived on average for 11.6 months, those who started it later for 8.9 months. In the process, this second group received more chemotherapy and spent more time in the last 4 weeks of life on an intensive care unit.

If the patient is no longer able to decide himself we ask if there is a living will, if possible with lasting power of attorney. In the first section, a living will describes certain phases of illness, such as a terminal phase that has already begun or irreversible brain damage. If these occur, the subsequent wishes of the patient, such as refusal of life preserving treatments or provision for sufficient mitigation of symptoms, are to be carried out.

In not a few cases, the current state of the disease is not included as a precondition for the subsequent wishes regarding treatment. And at what point do we know if brain damage is irreversible or if a coma has become long-term?

If there is no written living will, we have to try and find out what the presumed will of the patient is with recourse to earlier expressions of that will. As well as relatives, we can ask a family doctor who has known the patient for many years.

Frau L. had been for many weeks in an out-patients' clinic when she was admitted to our palliative care unit. Trauma to the bladder with subsequent urosepsis had resulted from a failed surgical attempt to remove a local recurrence of a rectal carcinoma, followed by respiratory failure with 4 weeks of artificial respiration and resuscitation from cardiac arrest due to a coronary event. Her blood pressure was now stable, she was breathing easily, but was extremely weak and mentally not in a position to understand her situation. In the letter of admission there was a note that Frau L. was married but had no children, and that a power of attorney had been set up for her. When asked about her husband, she said she thought he was in another hospital. A phone call to her GP allowed us to clarify her situation: her husband had been in a care home for years because of Parkinson's and dementia. We discussed her presumed wishes with her GP; until she fell ill, she had faithfully visited her husband every day in the care home. Through our social services we organised for her to be accommodated in her husband's care home.

If it is not possible to determine the supposed wishes of a patient, the practitioner must make a medical decision for the benefit of the patient. Protecting life carries great weight in that decision process.

The second basic precondition for treatment is the medical indication. Indication comes from the Latin 'indicare', to show. 'Indicare' does not just include the diagnosis of the illness, but of the whole patient: is he suited to this treatment or not? If there is, on the other hand, no indication for a certain treatment, there is no need for us to speak to the patient about it – unless he asks about it. Then we need to explain why this treatment is not under consideration. I'm often asked why metastases in the liver are not an indication for being given a liver transplant. Metastatic disease of the liver as part of advanced [primary] cancer is not an indication for a liver transplant.

Herr R. was 78 years old when he was admitted to our hospital. A year before, he had been operated on successfully for stomach cancer. A few months ago, tests had revealed metastases in the upper abdomen. During the chemotherapy he started as an out-patient his condition seriously deteriorated. He had lost a lot of weight, pains in his chest and lumbar vertebrae left him in continual discomfort. He was so weak he couldn't get out of bed without assistance. In my first contact with him he appeared sad and depressed. "I don't want to carry on living like this," was one of his first sentences. "But you're not to help in that direction," he added with a gentle smile. "You're right," I replied, "but may we help treat the pain?" We agreed that we would treat his pain (an absolute indication) and at the same time be permitted to look into the causes of his back pain (relative indication). We initiated a whole series of tests such as CT scans of his chest and lumbar vertebrae, laboratory tests and a lumbar puncture, without being able to explain the cause of his back pains. Simultaneously, his pain was treated with Metamizole, opiates and Pregabalin, which kept it at a bearable level for him. Despite daily physiotherapy he became increasingly weak, until after a week he had paresis in both hands. Calm and composed, Herr R. repeated the first words he had said to me and expressed the view that he wouldn't be alive in a few days' time. I agreed and said that was very likely. But I said I was still uneasy about not being able to ascertain the cause of his condition. Would he allow me to arrange an MRI scan of his cervical spine? I hoped to find a cause for the weakness in his hands that could be treated. Again, he agreed. By the time the examination could be carried out on the next afternoon, he had lost movement in both hands. The MRI showed an abscess between the seventh and eighth vertebrae with prevertebral extension and extending into the epidural spinal canal. We asked for a consultation with the neurosurgeon whilst pointing out that the patient was terminally ill with cancer. I was then surprised how quickly he agreed to the neurosurgeon's offer of an operation that same evening. My expectation was that

Herr R. would turn down the offer. Before his admission to neurosurgery I pressed Herr R.'s paralysed hand and said to him: "Herr R. you wanted to die quickly with things as they are. Perhaps the Lord God will grant this during the operation. Or you will get better again." Herr R. was operated on the same evening and the abscess was removed.

Herr R. had given express permission for us to carry out physically distressing tests. We for our part made every effort to give him the pain killers he needed before every test.

If a patient is being given palliative care, we can discontinue many of the medicines that had been taken regularly for years previously. Cholesterol reducing medication, drugs used in treating diabetes (patients hardly eat). The rare blood tests we do are done only to prevent any 'derailments' in an upward or downward direction. Above all, we do have to ask if this or that test has any consequence. Many anti-hypertensive drugs need to be stopped; the patient is already hypotonic owing to weakness and loss of weight. If it is not possible to swallow tablets, the necessary drugs (e.g. pain killers) are given in other ways: as a suppository, subcutaneous injection, plaster or nasal spray. The number of infusions should be urgently reduced or completely stopped. Pulmonary oedema or respiratory secretions produce avoidable symptoms. Thirst cannot be quenched with infusions. Regular oral care with drinks which give the patient taste and enjoyment provide for this.

Palliative medicine is an 'easy' medicine: we 'only' have to look after the patient's discomfort, and we don't have to fight for every opportunity to prolong life. We need to control symptoms; we can leave to God our concern as to when life will end. When asked about this, I can say to many a patient: "We have a power above us that decides how long you may live." Or I can explain: "Here on this earth is just our second home ..." This light-heartedness in our work allows us the possibility of confronting the serious situation with humour. In doing this we must in no way laugh ABOUT the patient, but WITH him. Laughter is the healthy and defiant reaction of not having to take the bad situation seriously. The situation must lend itself to this. Clinic clowns bring humour as a consequence of their profession; we should use it in correct doses when the situation is appropriate.

We needed to insert a catheter into the vein of a 26-year-old Chinese patient with very advanced cancer in order to give him medication. His young girlfriend insisted on staying in the room whilst I put in the catheter. More to distract her than anything else, I tossed her the instructions for inserting the catheter from the sterile pack. I asked her to read it to check I was doing it properly. Shortly afterwards, she laughed out loud: the various languages included Chinese.

Palliative medicine is a 'difficult' medicine – when the patient is a similar age or even younger than we are. When we are made aware of the finality of our own lives (Psalm 90, 12). When the patients cry and tears well up in our own eyes. We may also at this time shed – a few – tears. Tears cleanse the soul. But they must not overwhelm us. We should be grateful for our own strength and health. For the opportunity we have to help others. Sharing in grief means standing by others and persevering, but at the same time being unable to change anything about the situation. That can give consolation.

Attending to patients at the end of their life bestows wisdom. We should be quick to listen and slow to speak (James 1, 19). Those people in front of us have only a little time remaining in their illness; a whole life lies behind them. Many tell of amazing things from their lives and how they have mastered difficulties. It is worth paying attention and making time for them. Offering to be with them on the last stage of their journey makes patients more confident in the face of the imponderable. Many have no fear of death, but are afraid of the process of dying. We must not think : 'I alone could do that, or I could do it the best!' Be assured that a whole team is working with you; you as a doctor cannot be there all the time. A team carries the patient; I as an individual would be overburdened. I can burn with passion for the work, but I need to beware of being ‘burnt out’. It comforts me to know that I am, as a consultant, not the most important member of the team. After all, Jesus promised us: “I am with you every day till the end of the world.” (Matthew 28, 20)