

Narrative Approaches in Patient Information and Communication

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TRUTHTELLING OR TRUTHFULNESS

TRUTHTELLING IN REAL-LIFE SITUATIONS

Life is a process, and life stories are histories in development. Individual stories are interconnected via family, neighborhood, work, in love or hate, in understanding or misunderstanding, in being open, truthful or in hiding the truth or part of the truth or in lying. Different to scientific data, there seem to be different kinds of truth in real life situations, depending on the situation and the stakeholders involved. ‘What is truth?’ asked Pontius Pilate, when the Jews brought Jesus and requested that he be killed because he was a revoluzzer; 2000 years later there still is no consensus on who that man really was: a saint, a God, a wise man, a rebel, a teacher of love?

There are different kind of truths, (a) truth supported by fact and data, (b) truth supported by the interpretation of fact and data, and (c) truth supported and expressed by attitude. Also, there are different kind of reasoning, (a) reason as logical calculation and analysis, (b) reasoning from prudence, and (c) reasoning from the heart. Yes, there is a logic of the heart, *logique du Coeur*: ‘Le coeur a ses raisons que la raison ne connait pas’, said Jean Pascal: The heart has its reasons which reason cannot understand. The heart might have more than one reasons, more than one kind of truth. As far as medical treatment and consultation is concerned, famous 16. century Confucian doctor Gong Tingxian in his ‘10 Rules for the Physician’ requested in the first place that they ‘adopt a disposition of humaneness [ren]’; only in the fourth place he requires expertise in diagnosis: ‘they are to recognize the causes of disease; they have to be ready to speak about life and death; only physicians who attain this stage are experts in their field’. It is important to note that Gong Tingxian does not accept expertise as simple data correctness, but as professionalism in talking to patients about crucial data in a humane [ren], kind [ci], sincere [yi], and compassionate [ci] manner [6].

To explain this complex epistemological and ethical situation, I will cut across hundreds of arguments and dozens of definitions and options and, instead of reading an

analytical philosophical essay, tell a story. *'One day, Moses, the prophet recognized by Jews, Christians and Muslims alike as a true believer in God, fell ill. His doctors wanted to give him medicine, but Moses refused to be treated. He argued, that if God, the Almighty and Merciful, had given him this sickness, then God would relieve him at a time of God's choice. The next day, Moses condition got worse and the physicians came back, saying: Moses, God, the Almighty and Merciful, created the world and everything in it; God also gave us doctors the intelligence and gift of medical research and medical treatment, allowing us to find out about the healing powers he put into nature and to produce remedies for healing and for alleviating pain. Moses was convinced, took the medicine, and got well.'* This story is rarely known to Jews and Christians, as it was narrated by famous Iranian scholar and scientist Al Ghazali [6]. The doctors did not have to tell Moses that he was ill; he knew that and he had his own story on it: given by God and eventually been taken away by God. The doctors did not lecture Moses about the properties of medicinal herbs, rather they went into his story and tried to change his narrative about God's and his relationship in order to change the mode of coping and get his compliance with the plan of treatment. 'Telling the truth' in the clinical setting is not about curiosity, it is about actions to be taken, by the physicians or the patient or both. Telling the patient about crucial data, is not about those data, but a message to get things going. To 'get things going' was the reason the patient came or was brought to the doctor.

There is a small Christian community, Jehovah's Witnesses; they refuse blood donation as they interpret the holy texts that God forbade it. For Jehovah's Witness members it is crucial information that they will need a blood infusion or might die. For them it is the choice between to die soon and end up in eternal paradise or to die later and end up in eternal hell. This is not the doctors choice, it is the most crucial choice to be made the patient alone. The best way to tell the 'truth' is to routinely use the same approach as the doctors used with Moses, not lecturing about data and potential clinical outcomes, but going into the life-story of the patient and use his or her terminology and focus. But more often than not, these kind of patients will stick to their position and rather die than end up in hell.

The narrative about the prophet does not display truth about the existence of a Gods or other invisible powers or the existence of that particular God, the prophet and probably also his doctors believed in. The story also does not state as a true fact that those doctors were good doctors professionally and that they choose the right remedy; it only states, that Moses recovered, what he might have done with or without herbal remedy anyway. But the story presents the clear and definite fact that true believers in the almighty and merci of a God can understand reasonable arguments for accepting medical intervention. Is sharing one's blood with others genuinely immoral or is it an act of humanness? Is cultivating human stem cells or manipulating human DNA in

cloning for therapy immoral or ethically required to reduce suffering of the sick and to support life, is it an act of merci [karuna] or beneficence [maitri] as Buddha would have said. Is intensive medical intervention such as organ transplantation or in-vitro-fertilization or intensive surgery natural or unnatural; strict Taoists have very distinct opinions about these issues, most of them not shared by their doctors; but those opinions and attitudes are a part of their life-story in progress.

Do invisible things truly existing, spirits, Gods, a metaphysical world, a pre-established harmony in nature, the Tao? Some think, they do, others not. German rationalist philosopher Immanuel Kant has argued, that things transcendental, i.e. not visible and not experienced in time and space cannot be proven to exist nor to not exist. So, the stories about God or Gods, about immortality of the soul or re-incarnation, or a pre-established harmony of Tao might be true, indeed. But is it to the doctors to decide what is the 'real truth'? Not all 'truths' can be true at the same time, but many can, even though they might contradict each other. Greek philosopher Plato compared the violin as a visible thing to music, as something not visible. He argued that no one in his clear mind would ever doubt, that the existence of music is a true fact, even when at the moment no one plays the violin.

If a person in love, carrying a transplanted heart, says to her or his lover: 'I love you with all my heart', this might be a true or untrue statement, irrespectively that it is not her or his heart which is beating in her or him, but the transplanted heart from another person, man or women, now dead. The true lover tells the truth, when he says so; music truly exists even though invisible and sometimes not played; the doctors told Moses the truth about God's almight and God's blessing of medical research and treatment; Moses might have been untrue to his God, if he would not have believed in what the doctors argued. They told him the truth; they were truthful to his belief and to their mission. *True information on details of medical or other facts only occurs within a wider system of life-and-belief reference; communication-in-trust and cooperation-in-trust in medicine only is possible and efficacious if embedded into the stories of individual people interacting with each other.*

THE PRINCIPLE OF TRUTHFULNESS

The truth told to Moses by his doctors was his truth. It only can be generalized if everyone else shares the same assumption as Moses did. The existence of God, of an eternal paradise, of re-incarnation of the soul, these assumptions are not true to everyone. But it can be safely assumed that most people share as true other certain common-sense evidence and prudence. Common sense tells that risk prevention and being prepared for certain risk is the prudent way to do, even though we might disagree whether it is right or wrong to accept other people's blood or organs or to take medicine made from pig or cow tissue. Huang Di Nei Jing of the Western Han Dynasty referred

to the wise people of the past when making the point for preventive health care as common sense: *'The sages do not wait until the sickness is there, they cure the sickness before it takes place .. if only waits until the sickness is there and then uses medicine to cure it, that is no different from waiting until one is thirsty and then starts to dig a well'*. [6] In this narrative, the comparison between digging a well and preventive health care is so impressive that one does not depend on who told the story first. It is so self-evident that wells are essential providers of fluid and everyone would die without access to drinks, that this truth would not be less true if Adolf Hitler or Pol Pot would have first spoke about it rather than individual or collective of prehistoric or mythological Chinese sages of no known name. Everyone, including medical students and lay people, confronted with this story, will be impressed by the suggested factual parallel between prudent water management and prudent health management.

What is the truth, to be told to the patient in the clinical setting? The full truth is that diagnosis and prognosis and the efficacy of therapy quite often is uncertain. The correct answer to the patient in many cases therefore would be: 'I don't know'. But people don't come to the doctor to be told that the doctor does not know, has certain assumptions about the interpretation of diagnostic data and cannot exclude other interpretations, is uncertain about the future course of the disease, cannot predict with certainty the efficacy of treatment in any particular individual case nor particular side-effects. Is this the truth you want to share with your patients, who came to you for cure and pain relief? Life is a story-in-time, a story-in-development. In the clinical setting life is a story of disease, diagnosis, prognosis, treatment, hospitalization. These are stories-in-time; so are physician-patient interactions and so are the modifications in communication-in-trust and cooperation-in-trust between patients, doctors, nurses, the ward environment and the family environment.

Given the situations-in-progress scenario in the clinical setting, it is not cynical to say, that truthfulness rather than truth-telling is the more appropriate term in interpersonal relations, in particular when different people make different assumptions and have different visions about true reality. If we need a bioethics principle related to information and data communication, it is truthfulness, not simple truth-telling as we do in science. In science and research there are certain data false or true; in the court of justice certain stories are a lie, others are true, others half-the-truth. Honesty and sincerity of information and communication do not depend on the content of information alone, they also depend on the scenario and the people involved, their visions and hopes, their fears and their anxieties, their uncertainties and risk competence. Information always is embedded in an actual situation; the present situation is embedded in a story, containing a past and having a future, which might be more or less open and clear, more or less pleasant or unpleasant, more or less certain or risky. *All communication is embedded in a story, therefore truth-telling is part of the*

wider enframing story, in everyday life and in the clinic. If we cannot interact with information from our own life-story, then such information is uninteresting, nonsensical, has no true value for us.

NARRATIVES IN THE CLINICAL SETTING I: BASIC ISSUES

We tell patients stories for different reasons, but above all, because, whatever we communicate – by means of just giving data, of interpreting data, of making suggestions or requesting consent or compliance – they will integrate into their own life-story, into which they are entangled. And we need to know about the life-story of the patient, her or his visions, experiences, disappointments and hopes in order to integrate that value status information into individualized diagnosis, prognosis and treatment decisions. Basic knowledge about the patient before the beginning of any treatment needs to include answers to these basic 3 questions: Who is this person? How much does this person want to be involved in treatment decisions? Who else could be a partner or confident in clinical decision making? Not only diagnosis and prognosis, but also treatment decisions, review of treatment, governance and clinical ethics consultation will need to use this kind of information and integrate it into decision making [4:123-130]. Especially when cases become crucial, it is essential to take the patient's value history as adequately as taking her or his medical history.

The following 3 stories are just examples of how to cover a short list of important information we need to have about visions, values and wishes of patients as far as their health care treatment is concerned. We ask the patient to tell us something about herself or himself; then we tell them stories to find about her or his will or competence to be actively involved in treatment decisions and who else, if not the patient, might be a preferred and trusted partner in information and cooperation. We try find answers in a narrative manner: (1) what can the patient tell us about her or his own experience with health and disease issues, pain and suffering, coping and compliance; (2) what kind of truth wants the patient be told by a truthful doctor in a communication-in-trust and cooperation-in-trust relationship; (3) how far should the family or friends be involved in telling and deciding, who is the preferred speaker for the patient, who is not?

(1) As most people are not familiar with the clinical setting and as they might face the reality of severe or chronic illness for the first time, it is important to elicit information about the patient's experience-and-competence level of dealing with health risk, disease, hospitalization. *We need to learn about the life-story of the patient, so we can integrate their value status together with the medical status into a truly personal status.* According to Paul Ricoeur there is a correlation between the telling of a story and the temporal character of human experience. Experiences and the way we review and evaluate previous experiences shape the way we tell the story of our life. This

telling of my own story might have deficiencies related to my competence of finding the right words and the appropriate principles of vision, fear, hope, and self-experience. If the patient's response is rather weak or poor, then we can assume that our own story of communicating and cooperating with him might be more complicated than otherwise. Using a method of soft-paternalism we try to elicit values and visions from patients as far as they are related to health and disease, coping, compliance and their expectations. This is a story of how we try to use the narrative approach to let the patient tell us her or his experience-in-progress story related to health and disease; we ask the patient: *'Stories of fatal disease, suffering, and dying are catalysts for the recollection of one's own often unpleasant and agonizing experiences. Many of us have our own stories to tell, stories that have already become a part of our own life histories. What are your stories? What has become a part of your life story? (1) Have you been in the hospital before? Why? How long? (2) Has own suffering or illnesses of loved ones or friends become a part of your own history and influenced your understanding of disease and pain? (3) Have you been a witness to death and dying? What were your reactions and impressions? What still moves you?'* Some patient will not have to or do not want to tell much; some tell a lot, relevant or irrelevant for their care; but, whatever they tell or not tell is an important contribution to be included into the value status of this particular patient, subsequently in diagnosis and prognosis, in treatment decisions, in reviewing treatment, in governance and in ethics consultation.

(2) What 'truth' does the patient want to be told; what is her or his very personal wish-and-value history into which communication and cooperation has to fit? We tell the following story about an incurable cancer case and ask 4 questions: *Mrs. M., 38-years-old, had her left breast removed five years ago because she had breast cancer. Now she has increasing pain in her lower back; her physicians have diagnosed metastatic bone cancer. They recommend chemotherapeutic treatment to reduce pain and to prevent or to slow down the development of more metastatic cancer. Mrs. M. undergoes chemotherapy with uncomfortable side-effects. Her pain increases and is not treated adequately. The physicians do not tell her the "full truth," that chemotherapy will not cure her cancer, but might prolong her life. Mrs. M. dies in the hospital eight months after the bone cancer was detected; she did not die at home as she had wished. Without chemotherapy she might have died a few months earlier.* - 1. How would you have wished to be treated? - 2. Would you want your physicians to fully inform you about your condition, even if it is terminal? - 3. Would you want intensive and aggressive pain treatment, even if it might reduce your mental alertness? - 4. Rewrite the story you would like it to end! Question 1 and 3 address issues of 'will to live' and the intensity of aggressive medical care together with aggressive or non-aggressive palliative treatment; answers might be helpful in giving an insight into the patient's wishes and values in regard to treatment and palliative care in general.

More important for the truth-telling issue is question 2, and we got quite a variety of responses of nearly all possible answers [:84f]. Answers included the following: 'I cannot trust a doctor who does not tell the full truth'; 'I want general information about the sickness, but no clear details about terminality or life-expectancy as this would hurt my will to live and to hope'; 'I want to know as much as I need to prepare my leaving from this world'; 'yes, because certainty is better than uncertainty'; 'that information needs much better "packaging" than the news in the television; 'yes, but I don't know I would react and whether it would be good or not'; 'yes, so I can use the remaining time for good living'. My message to you in presenting some answers in this basket of dozens of answers we got, is that as life-stories of people are different, so are their wishes, fears, and uncertainties about the 'truth'; this does underline the fact that they request true and trustable truthfulness as an attitude and character trait of the physician rather than some raw data or lecturing from textbook knowledge.

(3) In the United States it is widely assumed, that patients need to make autonomous decisions; in Europe this is not always the case; in Asia it is assumed that families rather than sick individuals be trusted partners for physicians in decision making, even though cultures and attitudes are changing. How to act in such a situation? We play the issue back to the patient and find out more about her or his decision making culture and competence and about family relations and support networks. We have told the following story: *Mr. B. is 79-years-old and dependent on others. His eyesight and hearing have diminished. He seems to have lost all interest in life. At times he is very confused and does not even recognize others. He has pain in his legs and can only walk short distances, because of poor blood supply to his legs, which is caused by previous smoking. Blood vessel surgery might improve his mobility and reduce pain, thus improving his quality of life. Mr. B. does not understand the situation nor can he make his preferences clear; he does not have an 'Advance Directive', nor has he named a proxy. One daughter and the physician favor surgery while the other daughter is opposed.- 1. If you were in Mr. B.'s situation, unable to decide for yourself, who should decide for you, your son or daughter, both together, your spouse or friend, your physician, who else? Give names and addresses. - 2. How closely should physicians follow advance directives?- 3. How would you have wished to be treated?- 4. Rewrite the story the way you would like it to end!*

When we ask the patient to rewrite the story, we achieve a couple of goals: (a) we make clear, that is the story of someone else, not a mirror of the patient; (b) the patient is asked to situate herself or himself into the story of someone else and express her or his wishes and preferences for treatment; (c) the patient is invited to freely modify the story in narrative form so that no arguments need to be given. He or she is given the opportunity to picture a world he would like and to tell a story he would like to live in.

NARRATIVES IN THE CLINICAL SETTING II: SPECIAL ISSUES

There are quite a number of situations where we cannot communicate with the patient due to the specific character of the disease, but it would be very helpful, if we would know in advance how the patient might have judged special situations of health compromise and disability. These are the cases of dementia and severe dementia, of long lasting coma, of losing the will to live. We have used narratives to help patient to prepare themselves for signing individualized Advanced Directives. But in doing so, we recognized that using stories and responding to stories has an end in itself; patients learn about themselves, their values, visions and wishes, also what they might want to do or what they abhor. We have found out that it is more authentic if doctors use stories they themselves have been involved in rather than taking narratives from books [1:320-322].

This is the story of SUDDEN BRAIN DAMAGE: *Ms A, 55, suffers from stroke in her office, a result of many years of inconsistent hypertension control. An accumulated blood clot in the brain tissue cannot removed surgically without major additional brain damage, but may disappear in part or totally over a period of several months. At this point it is unpredictable which neurological damages will remain. They can vary from partial or total paralysis to partial or total loss of cognition, speech, memory or thinking. - 1. Which bodily or mental disabilities or defects do you think would allow you to continue a life worth living? - 2. Which neurological defects would you think are so severe that you would not want to continue living and therefore refuse all medical treatment, including treatment of infections and minor injuries, while at the same time continue to accept treatment against pain, restlessness, angst, also foods and liquids? - 3. Which damages would be so severe that you would want to have palliative and basic care only, so that you would be allowed to die as soon as your body allows you to die? - 4. Rewrite the story the way you would like it to end!*

This is the story of LOSING THE WILL TO LIVE: *Mrs. S., 80-years-old, is alert and competent but suffers from heart pain and arthritis, in addition to her often painful and incurable intestine inflammation. Her two sons are living in another state. Since her husband died two years ago, she has lost the will to live. She told her family physician about her plans to commit suicide and asked that her decision be respected. Now, she calls the doctor and tells him that she has taken the necessary pills and wants to die in peace and not be revived or put into the hospital. A few hours later, the doctor makes a house call. No one opens the door, and a neighbor lets him into Mrs. S.'s apartment. They find her lying on the couch unconscious and a note on the table reading, "Please, let me die!" The doctor follows her wishes. A court did not hold him responsible for not saving her life. - 1. Can you imagine that you would act like Mrs. S. in similar situations? - 2. Would you want your doctor to give you detailed information on how to commit suicide or even assist you in doing so? - 3. How do you evaluate the doctor's reaction in moral and in legal terms? - 4. Rewrite the story the way you would*

like it to end!

This is the story of PROGNOSTIC UNCERTAINTY: *Mr. W., 26 years old, survives a motorcycle accident with severe fractures of the cranium, of the hip and the right leg. His spleen and his right kidney are injured and have to surgically removed; two days later the right leg becomes seriously infected and has to be taken off from the knee downwards. Now, after four months, Mr. W. still is unconscious. The statistical evidence that he will awake from his coma is very low. He depends on artificial nutrition and on a mechanical ventilator. - 1. Would you want artificial nutrition and ventilation, if after some time, let's say 6 months, the probability that you will regain your consciousness will less than 1 in 10? - 2. What arguments support your decision? - 3. What are the mental or physical handicaps that might cause you to wish to be dead rather than alive? - 4. Rewrite the story the way you would like it to end!*

ADDITIONAL MODELS OF NARRATIVE COMMUNICATION

How to communicate with patients in acute care, in prevention consulting and in chronic disease care is still an issue for evidence based research and improvement. Telling the 'truth' is one aspect, but an aspect which need to be addressed within the life-in-progress and communication-in-progress story of this or the other patient. Narrative methods experimented with by others include (1) the 'script approach', (2) the 'value diary' approach, (3) the 'socio drama' approach [4:52-53].

(1) Seghal, a nephrologists in Cleveland, Ohio, has written a narrative script to prepare a patient for a potential onset of Alzheimer's disease. He tells the story of a dialysis patient friend whose mother has Alzheimer and the concern of his friend about the mother in case he would die earlier than she. The doctor also asks what the patient's spouse would think about this case. The doctor then modifies the story and asks: what if it were you or your wife? This script method uses the same slow-step approach as I have already presented, to talk about 'other people' first then move more closely into the patient's own life-story of hopes and fears. Sometimes this approach, even though sensible, is recognized by the patient as somewhat manipulative, because only after some crisscrossing of talk the final topic is addressed.

(2) Grundstein Amato in Jerusalem has proposed and experimented with a 'value diary' for semi-dement or dement patients. Here it is the nurse who makes the patient talk about the 'good old days' and everything they want to talk about. The nurse writes a diary after each conversation, then compares the various stories about consistence and underlying central attitudes, expectations, disappointments and fears of the patient. The diary then is used to determine best possible care based on the patients life-stories the way they still can tell those. This approach need highly qualified nurses and doctors; also it very time-consuming.

(3) The so-called 'socio drama' approach, in which nurses and other caregivers

play out a real life story of patient-and-doctor-and family such as abortion decisions, has been used widely as a means for stress reduction of caregivers. It also can be used to confront patients and healthy people with crucial situations they actually face or might face in the future, thus preparing them to be more competent partners in communication-in-trust and cooperation-in-trust with their caregivers. For issues of lifestyle modification in situations of obesity, addiction or chronic illness this kind of on-stage narrative has been used successfully.

NARRATIVES IN GENETIC COUNSELING

Physicians are not only treating patients, they help people – health people, presymptomatic people, carriers of different kind genetic health risk, people exposing themselves to lifestyle related health risk of different kind such as smoking, drinking, overeating, overworking, people exposed to environmental, job-related, family-related social or other kind of health risk – as advisors or counselors to understand their situation and health risk better. They will assist their counselees to find their own answer to central issues of lifestyle and attitude. It is required in many countries to have mandatory counseling before making final decisions about abortion. We have mandatory or voluntary counseling in addiction issues and in prevention of infection such as AIDS. Lecturing people about health risk by presenting tables of statistics or textbook information has proven to be quite insufficient and ineffective. Group therapies, where real people meet real people and tell their real stories, sharing the will for compliance, being aware of real risk of regression into addiction or re-exposing themselves to known health risk, - have been much more successful. While in group therapy participants tell their own stories, in one-to-one counseling sessions narratives are used to connect medical issues to real-life situations and to evaluate life-decisions, not statistical risk. The socio-drama approach qualifies in these scenarios, but also story-telling, in particular real stories in which the storyteller has been involved and can speak from experience.

We have successfully used a couple of stories, actually derived from the real-life story of one family being carriers of ADPKD kidney cyst disorder, a mother and her 4 sons, and another real-life story of a young pregnant girl of the same carrier type [2]. ADPKD is an autosomal dominant genetic kidney disease of late onset; carriers develop hypertension and growing cysts in their kidneys, requiring dialysis treatment or kidney transplantation at an age between 20 and 60. They also might have other medical risk such as developing aneurysms or cysts elsewhere. Prudent lifestyle management, in particular hypertension control, will postpone onset of clinical symptoms. Offsprings have a 50% chance of being carriers or not; precise time of onset is not predictable. Rita Kielstein, a nephrologists with extensive consulting and clinical experience in treating

ADPKD patients and I have developed a protocol for genetic counseling using stories for discussion and reflection and also for re-writing. As individual responses following information of crucial information, either genetic or disease related, will be different, some more understandable than others, we use these real-life stories as material, to which one can agree or disagree, but which might help to find one's way of coping and redirecting one's own life. Following is the script for a story-based counseling session:

SUGGESTED PROTOCOL FOR GENETIC COUNSELING IN NEPHROLOGY BASED ON ACTUAL STORIES OF PATIENTS

You have been diagnosed as a carrier of ADPKD, an inherited disease, which will continue to cause kidney problems and might lead into total kidney failure. Then dialysis treatment will be used as substitution therapy; also, kidney donation might be a possibility. We cannot predict, when your kidney will stop working. But you can influence the onset of total renal failure by good control of hypertension. You also should avoid contact sports and other activities which might cause ruptures of cysts. There might be other health risk associated with this genetic disorder which we can discuss at a later date.

May I ask you make three lists of questions, one set of questions you are going to ask me next time we meet, another list of questions you feel you need to ask yourself, and one set of questions to ask others as a result of this new information and situation? How good might you be in complying with good health risk management? Which personal values and wishes, fears and hopes will be influenced or modified by the new information?

STORY I: INFORMING AND ADVISING CHILDREN AND PEDIGREE:
'Mrs Winter, a carrier of ADPKD, has four sons, who might or might not be carriers of this genetic disorder. We suggested that she ask her sons to be tested. She is reluctant to tell, as she feels 'guilty' of eventually having passed the sick gene and as she does not want to 'get involved' in her sons life. On the other hand, she understands the benefits (as well as the burden) to the sons who might be carriers, if they would know.' - How should Mrs. Winter decide? How should she have come to a decision? - Put yourself in the place of Mrs Winter and rewrite her story so that your resolve, values and goals can be implemented! - How will you decide? Which obligations to you feel to your immediate family? Which to your wider family?

As ADPKD is a genetic disease, the likelihood of your children or pedigree being carriers of the same disorder is 50%. It would be a relieve for them to know that they do not have the disorder. However, if they will be confirmed to be carriers, they will have a good chance to use preventive matters in postponing the onset of renal failure.

STORY II: MAKING A REPRODUCTIVE CHOICE: *'Anita at age 16 was diagnosed as a carrier of ADPKD. Her grandmother just had died and here mother was in dialysis. Anita decided that she never would want to have a child having ADPKD. When she became pregnant at the age of 21, she asked for prenatal diagnosis and was unambiguous that she would abort, if the test results were positive. The results were positive, indeed. Anita made an appointment for abortion, but never showed up at the scheduled time and gave birth in another town. She might have hoped that one day there would be a cure for her child (and her).'* - What other reasons might she had have to change her very determined resolve? Bonding to the embryo, not deciding for fear to make the wrong decision, closing eyes and escape to a 'new life'? - Put yourself in the place of Anita and rewrite her story so that your resolve, values and goals get implemented! - Who will help you in making the right decision? Which values and wishes, fears and expectations will play a role in your decision making? What decision are you going make? What will be the strongest arguments in defending your decision?

STORY III: MAKING A HARD PARTNERSHIP DECISION: *'Karl was 25 when he learned about his ADPKD carrier status. He and his fiance had intended to marry soon. They both wanted to have children and raise a 'normal family'. After briefly informing his fiancé about the diagnosis and that he did not want to burden her his genetic heritage, he dissolved the engagement.*

What might have been the reasons, fears and expectations leading Karl to end this relationship? Did he make the right decision? How should he have reacted? - Put yourself in the place of Karl and rewrite his story so that your resolve, values and goals get implemented! - Which values and wishes, fears and hopes would determine your decision? Would you include your partner in making partnership decisions and how? What would be your resolve?

STORY IV: MAKING A HARD CAREER DECISIONS: *'Paul was a 21 year old pre-medical student when he learned about his positive status as an ADPKD carrier. After graduation he did not proceed with studying medicine many years to come, rather decided to find a job, make money, and to enjoy life while it lasts. He is now 42 years old, controls his hypertension well, does not complain about anything and seems to enjoy a happy single's life.*

Do you think, Paul made the right career decision? How much should genetic prediction of late-onset genetic disorders influence people's lives, plans, goals?' - Put yourself in the place of Paul and rewrite his story so that your resolve, values and goals get implemented! - How will the information about your carrier status change your values and goals in life, your fears and hopes?

STORY V: IS THIS THE RIGHT DECISION?: *'Albert, 32 years old, married and father of a 6-year old boy, was told that he was carrier of the ADPKD disorder, still without symptoms. He and his wife did not allow that their son be tested. When Albert*

developed the first symptoms of pain and renal dysfunction three years later, he committed suicide. He did not want to become a dialysis patient, as his mother was. ' - Do you think, Albert made the right choice in refusing dialysis treatment which he had not experienced personally yet? What role might his family played in his decision? Do you think he had discussed or should have discussed his decision with his wife? To whom else should he have talked before making such a definite decision? - Put yourself in the place of Albert and rewrite his story so that your resolve, values and goals get implemented! -

How will the information about your carrier status change your values and goals in life, your relationship to your family?

CONCLUDING NARRATIVE

I summarize my report with a story: it is the story of this article, its writer and its readers. It is an unfinished and open story of communicating about communicating with patients on crucial issues of treatment, the limits of medical knowledge, and the finality of life. I did not use the analytical method as it is not precise enough to analyze and to evaluate in an outcome-oriented way the issue of telling the truth to a patient. In reflecting on our narrative communication on one of the central issues in expert-patient relationship, we web this reflection into the wider story of how to serve the patient best, how to be a good doctor, a good nurse, how to combine beneficence with *merci*, as a Buddhist would say. The most appropriate way to communicate in the clinical setting this message that all life is story-in-progress and that our life-stories are intertwined, narratives are one of the prime instruments, often the preferred instrument. We can use it sometimes more, sometimes less, sometimes successful, sometimes in a disastrous way. *The life-stories of our patients and of us, physicians and ethicists, cross and interact for a short time. Physicians are in the driver's seat; they have to initiate trust and communication. In doing so, they have to learn as much from the life-story of the patient as she or he tells that story, maybe also with the consent of the patient how family members or friends tell that story. Health as life is a story in progress, not as the definition of WHO suggest a 'state of complete, physical, mental, and social well-being'. Health is a balance, changing over time, of acting and reacting and responding to others, to environmental or social risk features in our life's story in progress, including the entanglements with doctors, nurses and other expert [6].* The story-based understanding of health, being more complex and opposed to that of the WHO, comes close to what the Tao tells: 'Only when we are sick of our sickness shall we cease to be sick. The Sage is not sick, being sick of sickness; this is the secret of health' [3:no.71] It is to the doctors to help their patient to become like the Sages, to become sick of sickness. The actual medical story-in-progress, i.e. the reason and cause why the patient became a patient, can only adequately be understood within the wider

story of the patient and what the doctor needs to tell the patient about what she or he thinks the patient wants to know or needs to know. As health and disease as well as medical diagnosis and treatment are stories-in-progress, we prefer to use complete and detailed stories in clinical ethics teaching as only real-life-stories can present complex issues of patient-physician interaction [5]. As medical intervention, so are ethics consultation and clinical ethics stories-in-progress associated with other stories-in-progress.

Take the story of Anita. She was a person literate in ADPKD kidney cyst disease. She had seen her grandmother die and witnesses her mother in dialysis. She knows that she is a carrier. She has made up her mind to never ever give birth to a child who carries this disease. She is determined and makes an appointment for an abortion. But she does not show up and gives birth to a child she a ton of reasons not to give birth to. She did not comply with what she had determined to be the right and the most responsible road to travel. Her heart told her differently and her coping with her hereditary disorder changed accordingly. In telling her story here today, and in future medical counseling session, the message of this story is clear: every story is different; we are different; we change over time and we change in a short time if we are confronted with new information and challenge.

To communicate crucial information in the clinical setting requires to first learn about the patient and from his or her story, then sensibly walk into her or his stories and life-story and eventually establish a common story of mutual trust and respect. Such a story might be short-lived and related to the hospital stay, it might be a longer story of communication and cooperation in chronic disease management or that of addiction. Some stories of physicians interacting with patients and their families are sad stories, stories of broken or lost or never established trust, stories of half-truth or hiding the truth, stories of untruthfulness. This article tells the story that telling stories, listening to stories, and reacting to stories by writing one's own life-story is one of the ways to meet the challenges of crucial facts in the clinic, both by the doctors and nurses and by the patients and their families. But additionally the story reminds us that all life, individual and communal, is a story-in-progress, sometimes we fail, sometimes we are successful in intertwining our personal or professional life-stories with those of others, such as our patients who come with their own life-stories full of hope that the encounter with us in their and our life-stories will heal or help.

Stories are much more complex, efficacious and efficient vehicles for information and communication than simple lecturing, informing, or advising even can be. In some ways stories transcend the tellers and the listeners and the further the situation and the situation's story into the future web of this and other stories and lives in new entanglements. As the Tao says 'we make doors and windows for a room; but is these empty spaces that make the room livable' [3:no.11]. The room itself is full of

stories, our own's and other's . Prescriptions and procedures, rules, regulations and medical literature are like doors, windows, furniture. It is important, which stories we tell and act and get involved in with our patients and partners in these rooms and wards and if we act and interact, tell and listen entangled in attitudes of humaneness, sincerity, and professionalism.

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