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Non-Compliance after a Kidney-Pancreas Transplantation – A Narrative Case-Analysis Involving Different Patient-Physician Relationships and Ethical Frames

Background: Non-compliance is one of the most frustrating causes of long-term allograft failure. Despite the frequency of this phenomenon, the clinical-psychological approach has not yet been standardised.

Aim: To describe the use of a narrative approach based upon the identification of the best patient-physician interaction model and of the best ethical framework, in the clinical management of a non-compliant pancreas-kidney graft patient.

Methods and results: The case: a 30 year-old woman, diabetic since adolescence, recipient of a preemptive kidney-pancreas transplant. No psychological or behavioural problem had been observed or reported before transplantation. After the graft, a benzodiazepine addiction was diagnosed (withdrawal syndrome). She experienced two rejection episodes (low Cyclosporine levels), and discontinued steroids (Cushingoid appearance). She repeatedly refused psychological help and wanted to be managed by her physicians only. The three tested models were: parental-paternalistic (the "static model" according to Hippocrates and the "dynamic model" according to Moses Maimonides); self-determination of the patient; and therapeutic alliance. The four classic principles of the ethical approach (beneficium, non maleficium, autonomy and justice) and the narrative approach were also applied. Due to her psychological fragility, a paternalistic approach was chosen as the basis for the relationship. Furthermore, due to the problems in defining her "autonomy", and considering her benzodiazepine abuse, an integrated, dynamic, narrative, ethical approach was chosen. Pragmatic solutions required frequent clinical controls, as a means to supervise compliance. Despite occasional wide swings in her Cyclosporine A levels, she is presently well compensated, working full-time and free from further major non-compliance or drug-abuse episodes.

Conclusion: While this case raises several unanswered questions such as the practical classification of autonomy, competence and compliance, the definition of the setting of the patient-physician relationship and the systematic discussion of different ethical approaches may help the clinician to tailor interventions and to find adequate, tailored solutions.

Key words:

kidney-pancreas-transplantation, compliance, patient-physician relationship

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Non-Compliance nach Nieren-Pankreas-Transplantation – Eine narrative Fallanalyse unter Beachtung der verschiedenen Arzt-Patienten-Beziehungen und ethischen Rahmenbedingungen

Hintergrund: Die Non-Compliance stellt eine der frustrierendsten Ursachen für ein langfristiges Transplantatversagen dar. Trotz der Häufigkeit dieses Phänomens gibt es hierfür noch keinen standardisierten klinisch-psychologischen Ansatz.

Ziel: Für das klinische Management einer Nieren-Pankreas-Transplantatpatientin mit mangelnder Compliance soll die Anwendung eines narrativen Ansatzes beschrieben werden, basierend auf der Identifikation des besten Modells für eine Arzt-Patienten-Interaktion und des besten ethischen Rahmens.

Methoden und Ergebnisse: Es handelt sich um eine 30-jährige Frau, die seit dem Jugendalter unter Diabetes leidet und in einer präemptiven Transplantation mit einem Nieren-Pankreas-Transplantat versorgt wurde. Es wurden vor der Transplantation keine psychologischen oder verhaltensbezogenen Probleme beobachtet oder berichtet. Nach der Transplantation wurde eine Benzodiazepin-Abhängigkeit diagnostiziert (Entzugssyndrom). Die Frau erlitt zwei Abstoßungsepisoden (niedrige Cyclosporinspiegel) und setzte die Steroide ab (Cushing-Syndrom). Wiederholt lehnte sie jede psychologische Unterstützung ab und wollte ausschließlich von ihrem Arzt betreut werden. Die drei untersuchten Modelle waren: 1. paternal-paternalistisch (das „statische Modell“ nach Hippocrates und das „dynamische Modell“ nach Moses Maimonides); 2. Selbstbestimmung des Patienten und 3. die therapeutische Allianz. Es wurden auch die vier klassischen Prinzipien des ethischen Ansatzes (beneficium, non maleficium, Autonomie und Gerechtigkeit) und der narrative Ansatz angewendet. Aufgrund ihrer fragilen psychischen Verfassung wurde als Basis für die Beziehung ein paternalistischer Ansatz gewählt. Darüber hinaus wurde aufgrund ihrer Probleme, die eigene „Autonomie“ zu definieren, und angesichts ihres Benzodiazepin-Missbrauchs ein integrierter, dynamischer, narrativer, ethischer Ansatz gewählt. Pragmatische Lösungen erforderten häufige klinische Kontrollen, um die Compliance zu überwachen. Trotz gelegentlich breiter Schwankungen in ihren Cyclosporin-A-Spiegeln ist sie momentan gut eingestellt, arbeitet ganztags und ohne weitere größere Episoden von Non-Compliance oder Medikamentenmissbrauch.

Schlussfolgerung: Während dieser Fall einige unbeantwortete Fragen aufwirft, wie z. B. die praktische Klassifizierung von Autonomie, Kompetenz und Compliance, könnten die Definition des Settings der Arzt-Patienten-Beziehung sowie die systematische Diskussion über die verschiedenen ethischen Ansätze dem Arzt dabei helfen, die Interventionen patientengerecht zuzuschneiden und geeignete individuelle Lösungen zu finden.

Schlüsselwörter:

Niere-Pankreas-Transplantation, Compliance, Arzt-Patienten-Beziehung

Introduction

Non-compliance is a complex, widespread, possibly unavoidable phenomenon whose roots may be searched for in the individual's psychological, cultural-behavioural and physiological background (1-5).

In transplantation medicine, the phenomenon has been extensively studied in kidney graft patients, while diabetics are often considered the prototype of non-compliant patients in general medicine (6-12).

The entity of the problem is impressive. After kidney grafts, the frequency of the problem is reported as being very variable, mainly depending on the methods of diagnosis employed and on the definitions of non-compliance chosen; overall, the prevalence of non-compliance is highest in the paediatric transplant population, and is reported as being as high as 5-60% in the adult graft population (11-12).

According to the major internal Medicine textbooks, at least occasional non-compliance is almost the rule at certain points in the clinical and personal history of diabetic patients.

All the efforts aimed at an early diagnosis of patients "at risk", up to very negative approaches, are probably not only not completely sound from an ethical point of view, but also unpractical, due to the lack of reliable indicators: analyses such as the recent systematic review on non-compliance in the cyclosporine era, yielded in fact general remarks or identified very large populations at risk (younger, female, unmarried, and non-Caucasians) whose discrimination would be, at the least, quite unpractical (1). Furthermore, due to the elusive nature of non-compliance, there is at present no evidence in medical literature that even important episodes in the pre-transplant phase should be considered as reliable markers of post-transplant compliance, given that, at the time of the transplant, the patient has proven to be able to follow medical advice correctly (8, 13).

Last but not least, although in some Countries the physician is considered a sort of *warrant* of post transplant success (including the compliance issue), denying a transplant without any "evidence-based" proof that previous attitudes reliably predict compliance, particularly in the "high risk" younger

population, could open infinite legal (if not moral) controversies (8, 13, 14). However defined, non-compliance is an often-hidden, ever-present challenge for the transplant physician, as for all of those who take care of patients with chronic diseases; interestingly, most of the recent literature regards preventive approaches, diagnostic tools and epidemiological aspects, but the best clinical approach to non-compliant, single patients has still not been defined (1-13). An interesting point may emerge from a recent large survey, comparing different measures of adherence. Self-report at a confidential interview was indeed still the best measure of adherence for the detection of both missed doses and erratic timing of medication (14). Even if the authors concluded that such a diagnostic option is not directly applicable to a clinical setting, the minimalist attitude of abandoning a clinical role in such a crucial setting is fortunately not uniformly shared. If, on the contrary, the approach is still in line with a famous editorial on *The Lancet*, at the beginning of the present reevaluation of the patient-physician interaction models, the burden of this challenge is entirely upon our shoulders: If we physicians must survive we have to return to our roots of being teachers and healers (15).

The combination of two "high risk situations", together with the presence of a disease diagnosed at a pediatric age, as with pancreas-kidney transplant patients, may be expected to be an explosive blend, challenging the scientific and human skills of caregivers.

The lack of confidence with non-technical ethical or even philosophical issues, and the uncertainties of the physician's role in this ever changing, global society often make the approach to single patients even harder. In this context, the aim of the present report is to exemplify the application of the discussion of the patient-physician relationship and ethical frameworks as a tool to face the problem and to identify pragmatic strategies.

The Case

A 30 year-old woman recipient of a pre-emptive kidney pancreas transplant one year earlier: She had been affected by type 1 diabetes since adolescence

and had been irregularly followed thereafter, first in her homeland, later in our country. Her family history did not include kidney diseases or diabetes; however, both her parents had severe histories of alcohol abuse and her father had died of alcoholic cirrhosis five years before the present discussion.

She was diagnosed with severe kidney function impairment at the age of 25, after a miscarriage. Over the following few months, she underwent all the tests required to be waitlisted for a kidney-pancreas graft. During that period no alteration of mood or psychological imbalance was observed by the caregivers. She was repeatedly asked about her personal and voluptuary habits and besides moderate cigarette smoking, that she declared she would quit before the kidney transplantation, no drug or alcohol abuse was mentioned or suspected. She developed a close relationship with her caregiver, and appeared to be compliant to therapy: She followed the pharmacological therapy and a very demanding low-protein vegetarian diet supplemented with alpha-chetoanalogues. Her only transgressions were a couple of free meals, and she occasionally forgot to take her anti-hypertensive therapy - to her best recall less than once a week.

She received a pre-emptive pancreas-kidney graft in a different town, in October 2003. Immediately after the graft she experienced a period of acute stress; at this point the caregivers suspected the use of "self-prescribed" drugs and referred the patient to the local psychologist. The psychologist diagnosed a benzodiazepine withdrawal syndrome and proposed a program of slow tapering of the drugs, which she accepted. During hospitalization her Cyclosporine levels were very unstable, and she experienced an acute rejection episode, responsive to corticosteroids, during the hospitalization period.

Two months after transplantation, she came back to our town, where she now resides. Since hospital discharge, her levels of Cyclosporine A displayed a remarkably wide range, indirect witness of the presence of a major problem of non-compliance. The patient was controlled at least three times per week, and a psychological approach in the public setting was advised, but refused. Three months after transplantation, she experienced a severe episode of vomiting and confusion and was referred to

the Emergency room where her benzodiazepine levels were found to be very high (70 ng/mL). She was hospitalised in Nephrology but, despite the evidence of high benzodiazepine levels, she always denied their use. A couple of further controls confirmed her high benzodiazepine levels, but the caregivers felt that further controls would have been irrespective of her privacy. During hospitalization she also experienced an acute rejection episode, probably linked to the previous period of non-compliance.

During her stay in hospital she was visited by a psychologist who gave her initial support, and who offered to continue with a once monthly follow-up. After a few months however, she stopped going and did not want to meet the psychologist again.

In the following months she stopped corticosteroids twice, mainly for aesthetic reasons: Her features were in fact quite Cushing-like, and steroid withdrawal was suspected on the basis of the improvement in her physical appearance. The benzodiazepine levels were periodically controlled and were not always detectable (the patient was aware of the possibility of drug testing), but the Cyclosporine A levels displayed wide swings, witnessing the persistence of a non-compliant attitude. While the patient denied any error in drug therapy, she was aware that, due to her non-compliance, she was being controlled more frequently than the other patients. However, she has recently displayed a good compliance to clinical controls and laboratory testing, and has not experienced any serious problem in the last 16 months.

The Frames

Patient-physician interaction models

The patient-physician interaction models have been remarkably few in the history of medicine.

In the European tradition, history since Hippocrates may overall be summed up in just a few models (table 1) (16-26). As with proteins in biology, the preservation of their structure in spite of evolution witnesses their biological importance; similarly, in behavioural science, the preservation of a role witnesses its importance in the vital texture of society.

Tab. 1: Features of the main patient-physician interaction models and their most important practical and organizational consequences

Interaction model	Type of relation	Features	Communication	Example of organisation
Hippocrates	Paternalistic, static. The focus is on the doctor; the doctor prescribes the best care, taking into account his/her opinion of the patient.	Holistic, the physician takes care of the patient, in a setting of mutual trust; the patient gives the physician the "burden" of his disease.	Aimed to make patients trust the physician and accept his care; in the nature of the relationship the "best choice" of the doctor is implicit.	The physician explains the aims and scopes and reassures the patient on the feasibility of care; he reschedules the patient in a short time, to stress the importance of the "best care".
Moses Maimonides	Paternalistic, dynamic. The focus is on the doctor. The doctor prescribes the best care, as far as he knows, and suggest eventual alternatives.	Holistic, physician takes care of the patient, in a setting of mutual trust; the patient gives the physician the "weight" of his disease.	Aimed to make patients trust the physician and accept his care; the alternative options of care are elucidated to the patients, who have to understand the different possibilities of care.	The physician explains the aims and scopes and reassures the patient on the feasibility of care; the different options are clarified and the choice of the patient to follow a line of care has to be confirmed over time; he reschedules the patient in a short time.
Medicine as office work	Self-determination of the patient. The focus is on the patient. The doctor prescribes the best care.	Technical. The patient is free to choose what to do with his/her own life. The choice again belongs to the patient. The patient decides and asks for a specific act of care. Continuity of care is not part of the model.	Aimed at understanding what to do and how to do it; reasons and reassurances are not part of the relationship. The patient needs care and chooses the doctor.	The physician gives several details on the aspects of care. Since the choice to follow the care is up to the patient, the doctor is not interested in further follow-up and the patient chooses autonomously whether or how to continue care.
Therapeutic alliance	Alliance between different individuals of comparable value. The focus is on the relationship. Patient and doctor tailor a care that is the best one feasible, according to the opinions of both parties.	Holistic and tailored; the physician and the patients interact to get the best possible results for the single, specific case. Trust is mutual but the "weight" of the choices lies mainly with the patient. Continuity is the hallmark of the model.	Aimed at identifying the best pragmatic balance between the best care, as far as the physician is able, and the specific needs and quality of life of the patient. It's a mutual exchange of information and advice.	Both parties tailor care on the individual needs. Alliance may require an important initial investment of time, to modulate the care according to the patient's needs, and frequent contacts in the first period. Progressive autonomy may be gained by the patient.

The interest in this issue is not only speculative. A holistic model, as opposed to a model of patient self-determination, requires different hospital structures and medical approaches. Selfdetermination, where each medical act is singularly discussed by an expert or sought by the patient, requires a structure of hospitals as "offices". Continuity of care is not a hallmark of this

model in which chronic therapies are mostly seen as a series of separate acts, each requested by the patient. The hospital as health factories are the counterpoint of hospitals as homes or monasteries, where soul and body are cared for together, within an individual and exquisitely unique patient-physician relationship. This model is probably easier to find in a country with a

Mediterranean background, in which the long lasting tradition of medicine as a mission has not been completely forgotten (19). Continuity of care is a crucial point in such a model, in which a complex relationship between patient and caregiver is built as part of the therapy and considered more as a story rather than as the sum of single elements (27-31).

The models are not necessarily antithetical, and may co-exist during the care of a single patient (for example a patient whose pancreas-kidney graft is performed by a skilled surgeon, but whose chronic follow-up is up to a small caregiver team), with different boundaries, communication and organizational requirements.

Ethical models

Over the last decades, the health care landscape has been dominated by so-called *principlism* which considers simple and general principles as the basis of moral life, and whose roots are in the Nuremberg process, and in the following Belmont report and Helsinki declaration (16, 32-34). The four principles are: beneficium, non maleficium, justice and autonomy, the latter being supreme over the others (35-38). The tenets are that "in any given health care situation, any decision or course of action is morally justified if it is consistent with relevant principles, rules, background theoretical commitments, and particular judgments".

While this simple, straightforward and clear approach has its obvious advantages, its limits are mainly due to the difficulties of applying simple general principles to single complex cases. Therefore, a growing number of experts have begun to turn their attention to alternative approaches, overall more flexible and capable of catching different nuances of personal history and moral life (*manca nota*).

A very interesting approach, somehow specular to the rigid ethics of the four principles, is the so-called *narrative* approach.

The central tenets may be summarized as follows: "every moral situation is unique and unrepeatable and its meaning cannot be fully captured by appealing to law like universal principles" (39). In any situation "any decision or course of action is justified in terms of its fit with the individual life story or stories of the patient" (39).

Therefore, for narrativists, understanding an individual's life as a narrative is a complex and dynamic process requiring the integration between opinions of different experts and of different individuals, involved with different rules in the personal history of the patient.

In a way, principlists tend to simplify the individual's story in a clear, static, black and white photographic image, while narrativists face the challenge of trying to design a three-dimensional "tutto tondo" - world.

While the two approaches are not necessarily opposite, and may be integrated in clinical practice, we have chosen these two different scenarios to exemplify the application of ethical rules to our single case (39).

Definition of the questions

According to both approaches, the first step requires defining a set of questions; according to the usual approach to the patient's medical history. We have divided these into "past", "present" and "future".

Questions regarding the past:

1. In a patient with a family history suggestive of a severe alcohol problem, we could have probably suspected some pathologic trend towards recreational uses or abuses. However, up to which point should we, as caregiver physicians, investigate such issues?
2. The pre-transplant work-up also requires a psychological interview. While this is usually performed all over the world, the high rates of non-compliance recorded demonstrate that this tool is not sufficient to avoid further problems. What can be done in this regard?
3. After transplantation, when the severe benzodiazepine problem became manifest, our patient was supported by a psychologist, but she eventually interrupted the follow-up and did not want to see anybody else but her clinicians. How much should a physician insist and encourage a change of mind?

Questions regarding the present:

4. According to her choice, we did not insist she start a new psychotherapeutic path, and adapted our clinical setting to what we thought could better suit her needs (frequent controls, reinforcement of her well-being, et cetera); is this right? And consequently, to which

extent should mind and body be cared for by different physicians?

5. In a way, we consider having the relationship on our side, but we may not have the specific skills to face her psychological problems; however, even our relationship with her psychologists was not fully satisfactory, and we would have preferred a much stricter contact and closer approach, not available in the structure; were we playing God, or did we play well?

Questions regarding the future:

6. At present, over one year after transplantation, we are making frequent controls; how long can we continue this way? Which are the alternatives?
7. Is it right to keep on using the control of her clinical status (which may be justified by her instable Cyclosporine blood levels) as the main instrument to control her psychological problem? What else can we do?

Case discussion in different patient-physician relationships

The approach to a patient who has several clinical and psychological problems and who may be considered as not fully able to manage her disease is a challenge in all models of the patient-physician relationship (40-44).

The easiest way to manage such a case is probably within a paternal or paternalistic model, in which the physician takes care of all major clinical decisions, and acts as a parent or as a guardian, even forcing the patient to change her decisions (45).

Such an approach is mainly based upon confidence and trust rather than on persuasion and explanation, and is little, if ever, modulated upon the patient's views and choices. The truth is up to the clinician; the patient has to be kindly "forced" to obey to the wise prescriptions.

According to this view, in both its static Hippocratic or more dynamic Maimonides version, the physician should inquire as far as it may be of practical advantage into the patient's psychological distress; mind and body are to be cared for by the same caregiver, and under-

standing and active participation in care are not one of the major therapeutic goals (46-48).

According to this view, the physician who took care of the patient by deciding what to do played this particular game quite well, pushing her to take her medications, and finding a familiar environment to help her follow her prescriptions correctly. The physician may have also overplayed a little bit, but according to Hippocrates and Maimonides, "playing God" just a little may be considered as an extreme nuance of the medical profession.

Always in keeping with this relationship option, the choice of using non-conventional *escamotages* is correct, such as employing clinical controls as a means of following her psychological distress as well, since the modality of intervention is subordinated to the final result (coping with medications). The physician, who knows what is right for the patient, should pursue the results by any means, even regardless of the patient's will. No solution is too unusual; none is too intrusive, if the final result is reached.

While pragmatically useful, this Machiavellian attitude (the end justifies the means) underlines the centrality of the physician's role and leaves a limited space for the patient's autonomy, a "must" in some of the most recent approaches to patient-physician relationships (46, 50).

If an interaction model based upon self-determination of the patient is chosen, the same pragmatic options that seemed sound and positive in the previous model are on the contrary wrong, as the physician should respect the decisions of the patient, even when their effects are presumably harmful. According to this interaction model, the physician is a technical expert, and his-her role is to give advice and foresee possibilities of the therapy and of the disease, but the borders of the relationship are strict and sharp and any intrusion in the private life and choice of the patient is banned (45-50).

The major limit of this approach is that it applies only in the hypothesis that all patients are perfectly competent and able to take independent, balanced decisions regarding their own health. While this tenet is probably not fully true for most of the patients, at least at certain times during their diseases, it is quite obviously wrong in the case of a patient

who repeatedly showed not only the strong tendency to abuse drugs, but was also quite determinant in her denial attitude. If the patient is not only sick in the body, but also in the mind, the physician should take care of the first aspect, while another expert should be the interface for the second. In this case too, the physician will not force the patient to ask for psychotherapeutic support, but the baseline reasons are somehow opposite: In the paternalistic model the physician is the carer of both; in the self-determination model he or she is a carer for the first aspect only, and does not intrude into the sphere of the second (19, 47-52).

However, if the competence of the patient is challenged, this model loses its ground and cannot be fully applied; an interesting paradox is that the physician should judge patient competence, but has no way of investigating in depth or of encouraging the patient to request a psychodiagnosis. The third, more interactive model of patient-physician interaction, therapeutic alliance, also requires some degree of competence at least; however, in a more dynamic patient-physician interaction, both parties define a common goal and the modality to reach it may change, according to the psychological moment, or to the specific phase of a disease (50-58).

As in any alliance, the "relative weight" of the allied persons may be different and the final decision may alternatively follow the physician's or the patient's first options. Therefore, even in the context of a therapeutic alliance the balance may swing towards the wise physician or the independent patient, thus leading to pragmatic solutions that are analogous to the first two scenarios; however, the participation of both parties is higher, at least at an empathic level, and the final responsibility is shared by both (50-58).

According to this model, each relationship defines the degree of intrusiveness, relative power and decisional weight allowed to each party; therefore, an act that may be just right in one case may be absolutely wrong in another and no precise boundary may be set a priori. The empathy required is higher and the mutual confidence is the requisite for this approach; in this context, each relationship supplies the instruments to tailor solutions.

Thus, if the common goal was to live a good lifestyle with a pancreas-kidney

graft, the physician could choose the best way to reach the objective, even by apparently forcing the patient to take a different decision: Such an approach is similar to a paternal relationship, with the important difference that the pattern is not given for granted: In this case the patient somehow chooses "to play the role of the child" and the physician "to play the role of the parent".

In the case discussed here, the approach was started as a therapeutic alliance, setting the common goal of a functional graft and good health; the patient desired a protected relationship, in which the physician could take care of her and "decide for her". Therefore, the pattern of therapeutic alliance was a "paternal" one, according to her preference, but with the further goal of helping her to develop as much autonomy as possible.

Case discussion in different ethical scenarios

It is very easy to apply three of the four basic principles to this case: beneficium may be identified with the maintenance of a pancreas-kidney transplant; non maleficium with the pragmatic solutions proposed (for example the frequent clinical controls); justice is not only towards the patient who should be helped to overcome this difficult phase of her life and disease, but also towards society, due to the importance of not wasting precious resources such as donated organs (36-39).

The problems arise with autonomy, thus re-proposing the same uncertainties and paradoxes found in the interaction model of self-determination of the patient.

As mentioned previously, the patient's behaviour in our case was such that serious doubts existed regarding her true autonomy and in this respect, the consequences of her choices were quite anticonservative and potentially dangerous. Thus, to follow her choice, and to respect her autonomous and apparently also conscious decision to taper and stop therapies, would mean respecting one principle only (autonomy) in sharp contrast with beneficium, non maleficium and justice (both of the individual and of society) (36-39).

While in Western societies, particularly of Anglo-Saxon background, the autonomy of patients is generally considered

as the leading principle, in Eastern societies, of Confucian background, this scale of values is not fit and beneficium is proposed as the leading principle. If this issue were accepted, the type of relationship implicitly chosen would be a parental one, in which the wise elders (physicians) have more power to choose for the best. Indeed, according to such a scenario, our patients could, even with some limits, have been managed also by a principlist approach, being beneficium the leading force and autonomy a subordinate point, to be progressively enhanced by a long-term emotional support and educational pathway.

On the other hand, if principlism is self limited by the rigidity of its central tenets, a narrative approach, more in keeping with a dynamic patient-physician relationship, may allow pragmatic and practical solutions, whose definition must be searched for in the individual experience of the patient. If a principlist approach based upon autonomy would lead to "let her decide", and a principlist approach based upon "beneficium" would lead to "let her be managed", a narrative view tries to find nuances to tailor interventions on what the caregivers (but, if needed also the friends or the family) think would be her occult wish (such as being managed as a child, possibly reminiscent of the many problems suffered by a child in a family of alcohol abusers).

As for the paternalistic and the therapeutic alliance approaches, nothing is too much, nothing is too intrusive, if it is good for the patient, or ultimately accepted and efficacious in reaching the target. Once more the difference is between a physician-centred role and a microcosm of people orbiting around the patient.

The caregiver's view: A narrative, ethical approach, in the context of a therapeutic alliance patient- physician relationship

The fragility of this young patient was and is a great problem for all of us: She perfectly understood the theoretical aspects of compliance, non-compliance and drug addiction-dependence; however she went through several major

episodes of non-compliance and of drug addition. Her professional role as a nurse made it even more difficult to explain and discuss subjects that she theoretically knew about, but that she removed or denied.

Furthermore, her family history (her father died of liver cirrhosis and her mother is an alcoholic, the latter problem discovered during tests performed to evaluate the possibility of a living kidney donation), suggests the presence of a very difficult background and therefore her attitude towards finding relief in drug abuse is not surprising.

Our patient is a very good liar; none of us ever suspected the presence of any important addiction or drug problem. Furthermore, the problem of drugs is often openly discussed in the context of an Outpatient Care Unit due to the large number of young patients. Aware of the fact that in our urban area up to 35% of the people aged less than 35 commonly use some kind of illicit drug (cannabis being the most frequent), we are in the habit of discussing these issues in a very flexible, non dogmatic way. Even if some of the patients openly discuss their past (or also occasionally present) habits, she always denied any problem even with her "colleagues". The problem unexpectedly surfaced during the pre-transplant visits. Considering her intelligence and skills in masking her habits, the young psychologist who took care of her during her non-compliant phase after transplantation was unable to realise the depth of her non-compliance problem and "trusted" her declarations which fully contrasted with what the blood tests actually revealed.

It is very difficult not to be affected by such a mendacious attitude and, while her captatio benevolentiae was very strong, some of the nurses and younger physicians felt "betrayed" by her behaviour, with the risk of further complicating the psychological picture and therapeutic alliance. Since the public "offering" of psychological support was not in keeping with her wish (no possibility to meet in a quiet place, always in the same setting, long waits in the corridor, no privacy and surrounded by other patients with different or similar problems, no possibility of being counselled in the afternoon after work, or to have counselling more frequently than once a month), she stopped going altogether.

As a senior physician, I must honestly say that I understand her pretty well; I

suppose this kind of approach would have never been accepted by one of us physicians, without any kind of psychological distress or problem.

Considering her strong bond with us as a group and with a few of us in particular, we decided on a common policy of frequent controls, trying to make her feel "supported and controlled" at the same time, as part of the follow-up of her pathology. She wanted to feel "normal", she needed our approval, and still, even if she denied any drug problem, her benzodiazepines were high for a long period, and her Cyclosporine A is occasionally still very low. She also wanted to look good and therefore, in the end we decided not to insist too much on corticosteroid therapy, which we could not control by the usual means, since no blood level was available, and to focus on the most important "graft saving" drugs: Cyclosporine A and Mycophenolate Mofetil.

The strategy was apparently successful: no major non-compliance episode has occurred in the last 16 months and she is presently well, working full-time and has found a new home and a new fiancée.

Conclusions

This story has no easy solution, and it raises more questions than answers.

The discussion of a sound and structured clinical-ethical interface has been essential in order to develop therapeutic-pragmatic strategies, to decide the best approach, case by case, and to set the boundaries. Such issues, hardly part of the cultural background of physicians, should on the contrary be viewed as precious tools in helping the complex, frustrating and fascinating efforts to overcome barriers, enhance empathy and in the end, finding a way to help our grafted patients to keep their donated organs as a sacred and precious treasure.

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