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Scientific Contribution

Should health care professionals encourage living kidney donation?

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Abstract. Living kidney donation provides a promising opportunity in situations where the scarcity of cadaveric kidneys is widely acknowledged. While many patients and their relatives are willing to accept its benefits, others are concerned about living kidney programs; they appear to feel pressured into accepting living kidney transplantations as the only proper option for them. As we studied the attitudes and views of patients and their relatives, we considered just how actively health care professionals should encourage living donation. We argue that active interference in peoples' personal lives is justified – if not obligatory. First, we address the ambiguous ideals of non-directivity and value neutrality in counselling. We describe the main pitfalls implied in these concepts, and conclude that these concepts cannot account for the complex reality of living donation and transplantation. We depict what is required instead as truthful information and context-relative counselling. We then consider professional interference into personal belief systems. We argue that individual convictions are not necessarily strong, stable, or deep. They may be flawed in many ways. In order to justify interference in peoples' personal lives, it is crucial to understand the structure of these convictions. Evidence suggests that both patients and their relatives have attitudes towards living kidney donation that are often open to change and, accordingly, can be influenced. We show how ethical theories can account for this reality and can help us to discern between justified and unjustified interference. We refer to Stephen Toulmin's model of the structure of logical argument, the Rawlsian model of reflective equilibrium, and Thomas Nagel's representation of the particularistic position.

Key words: autonomy, coercion, freedom, living kidney donation, moral obligation, psychology

Introduction

In most Western countries the waiting time for cadaveric kidney transplantation has increased dramatically. In the Netherlands this is 4.5 years on average, with approximately 1,100 patients on the waiting list and an alarming mortality-rate among kidney patients (20% a year). This pressing situation is similar in many other countries (Price, 2002; Gutmann et al., 2004). Health care professionals and health care policy makers have good medical and ethical reasons to promote the many options of living kidney donation (Hilhorst, 2005a; Hilhorst et al., 2005b). This donation has important advantages over cadaveric donation and donor risks are low. Living kidney donation helps patients to circumvent the waiting list and relieves them of the burden of dialysis. Furthermore, the kidney survival rates for living kidneys are significantly better (50% still functioning after 20 years; for post-mortem organs this is only 10 years). Indeed many patients seem to prefer living to cadaveric donation (Kranenburg et al., 2005). Facilitating any transplantation program also has important societal implications, as the end stage renal disease program consumes a considerable amount of the health care resources, e.g. in the Netherlands 1% of the health care-budget (De Wit et al., 1998). Both policymakers and health care professionals may therefore feel an obligation to bring these facts to the attention of patients and their relatives.

How actively, we ask, can or should this be done in the clinic? What kind of professional interventions in personal relationships is justifiable? In Norway, for instance, where the option of kidney dialysis is not widely available, doctors often take the initiative in contacting the families of kidney patients to ask them explicitly to consider living donation. Lennerling et al. (2004) have stated that "Recruitment of the donor represents a medical and moral responsibility." But at what point is such interference viewed as unjustified pressure? Living transplantation programs are increasingly taking place or being proposed, e.g. cross-over and list exchange programs (Kranenburg et al., 2004; Segev et al., 2005), altruistic (anonymous and non-anonymous) donations between strangers (Landolt et al., 2003; Hilhorst, 2005a), and payment arrangements accompanied by ethical constraints (Steiner, 2004; Kishore, 2005). These developments make it even more necessary to evaluate the counselling process and to ensure that the information provided is clear and helpful and does not deteriorate into propaganda. Moreover, greater insight is needed into the attitudes and beliefs of recipients and donors with respect to living donation.

As part of several psychological investigations (Kranenburg et al., 2005), we have contacted, among others, patients in the process of living kidney donation as well as patients on the waiting list for kidney transplantation at our centre. We studied the views of both patients and their relatives (family members, partners, friends) with respect to living kidney donation. We used structured, semi-structured and in-depth interview techniques to explore their knowledge of the topic and the information they received (i.e. risk perception, attitude, communication, family system, mutuality of personal relationships and views on the effect of a transplantation on these relationships). We tried to have them elicit the obstacles to transplantation as they perceived them, and possible measures that could be taken to remove those obstacles. Do these patients and/or relatives disapprove of the transplantation option? Are they positive but unable to find a donor? Do they have difficulties communicating with relatives about transplantation? Do they anticipate changes in their relationship with their loved ones? Do they need additional information? Are their fears or anxieties specific enough to describe? Why do they postpone making a decision, etc.? The results of this investigation, which in itself was already experienced by some as a far-reaching interference, will be published elsewhere.

In this article, we focus on the justification of intervention in light of the needs and views of patients and their relatives, as expressed with regard to living donation and transplantation. The article itself is structured as follows: given the various obstacles that people encounter (par. 2), and given the aim of professional interference (par. 3), we describe the shortcomings of prevailing professional ideals – non-directivity in counselling and value neutrality of information – and suggest another approach (par. 4). Then we go on to discuss the justification of interventions in personal convictions and fundamental beliefs (par. 5), and to portray the consequences for the counselling process and conclude that counsellors should be open to the particularities of a situation and sensitive enough to appreciate the moral weight of those particularities; moral language appears to be necessarily ambivalent, and general ethical concepts are inadequate (par. 6).

Obstacles: practical, fundamental and complex

Patients and their relatives initially encounter many obstacles that keep them from offering or receiving a kidney. Some of those obstacles are purely practical and health care professionals can often diminish or eliminate them. This might be achieved by providing more information, or a better explanation of the benefits or risks of transplantation, or a clearer view of the alternatives, etc. Crucial, however, is the way in which this information is presented (Oduncu, 2002).

Obstacles may also have a fundamental character. Some objections or doubts refer to fundamental beliefs; when, for instance, a potential donor says: *"I would not easily donate an organ myself, because I believe that the human body should remain a whole."* (NB: this and the following citations, though based on our research, are constructed depictions, for the sake of argument). Views on man and the human body are frequently reflected in terms of integrity or a *telos* (an ultimate goal), such as *"organs do belong – and are bound – to this body, and are not meant for another"*, or the view that living organs are not just a commodity: "*We should not treat organs as merely a product that has value independent of its natural locus.*" (Shannon, 2001; De Castro, 2003). Other obstacles have a more complex nature, for instance when a potential recipient makes the observation that "*I would never ever accept a kidney from a relative, because I am afraid that I will feel guilty when* *something goes wrong with my donor after the transplantation*." Note that medical, psychological and ethical considerations here are intertwined in a complex way.

The crucial question is whether and under what conditions it is acceptable to interfere in these practical objections, fundamental beliefs and complex convictions. We shall argue that fundamental beliefs are open to change and that showing respect for these beliefs does not necessarily imply that we should not intervene.

The aim of interference

In health care, it is quite common to interfere in the lives of individuals. Health care professionals make decisions in patients' best interests in situations where they are not able to decide for themselves. In general, however, kidney patients and their relatives do not fall within this category. Justification of interventions is based on 'patient empowerment': health care professionals seek to support patients and their relatives in making autonomous decisions (Bergsma, 1997). The aim of interference is to strengthen or restore the autonomy of patients and their relatives, and therefore to enable them to make well-informed judgments and be in control (BMA, 2004). Interference is therefore justified in the sense that it provides support and gives help. Later we will take a look at what it means to interfere in counselling, and more in particular, in fundamental beliefs.

In addition, it could even be argued that it would be unjust if some individuals took more advantage of the living transplantation program than others, simply because health care providers were not helping to remove the obstacles that prevent more reluctant patients and relatives from participating.

One particular feature of the situation, however, complicates this picture. We should note that concepts such as 'support' and 'help' may have a very different meaning for patients than for potential donors. What benefits do donors have when we turn them into patients? Is not the best advice we could give them that of staying away entirely from the donation process in the first place? We must find a way to deal with this double challenge.

Interference in counselling

Crucial issues in counselling concern the question of what information is appropriate, and how this information should be (re)presented. Prevailing concepts of non-directivity and value neutrality have shortcomings that make them unfit for supplying adequate guidance. We will show why, and suggest another approach.

Appropriate information is contextual and personal

Legislation requires that health care professionals fully inform patients about all relevant facts with respect to treatment and alternatives. The many treatment options on offer include: dialysis, cadaveric transplantation, transplantation within and outside families, and cross-over transplantation. Each alternative has its own benefits, disadvantages and risks. The professional and moral obligation to provide adequate and relevant information is not limited to providing medical facts. The obligation also includes the counselling process as a whole. It is a health care worker's duty to help patients understand the information, and to enable them to act accordingly. His/her concern should be not only to simply provide the information, but also to ensure that the patient has understood properly. Intervention should try not only to determine whether patients and their relatives require any additional information, but should also strive to correct misperceived information. The aim is to provide support for the making of well-considered judgements (Oduncu, 2002). In the context of genetic counselling, it is acknowledged that a right-not-to-know exists. Individuals may have their own (good) reasons for not seeking further information (or asking for it at a later date). Their wishes should, of course, be respected. This consideration places a clear moral and professional constraint on all counselling. This constraint can only be established through open communication, free from coercion, if patients are willing to share their reasons, which is obviously up to them.

A number of concepts are used to describe both the threats and ideals implicit in the counselling process. These include determining the point at which free decisions become forced, deciding when to apply less or more pressure, and differentiating between inducement and persuasion. Other factors that can harmfully affect behaviour may also include, for instance, money (Goyal et al., 2002) or gender (Biller-Andorno, 2002). 'Value neutrality' is often put forward as the guiding criterion with regard to the appropriate representation of information. But what exactly is meant by this concept, and can it be a guiding principle?

First of all, professionals should understand that medical information in the context of a health care relationship cannot be value neutral. Even so-called 'pure' facts will be understood within a certain context, and may, in this setting, comprise a moral appeal. For example, someone who calls out "She is bleeding to death", might also mean "We must do something about this and prevent it". The word 'must' is understood against the background of a conviction, i.e. the view that lives should be protected and saved, if possible, and that – as a rule – we prefer life over death. A statement such as "Each year you wait for a kidney increases your chances of dying", implies that "You'd better come up with a living donor". These examples demonstrate a second feature of providing information. Since each piece of information is interpreted and experienced within the context of a person's views and earlier experiences, information is always person-relative. Questions such as "What represents a great risk?", "How great a burden is it to be on a waiting list?", or "Should dying always be prevented?", do not allow for objective answers (i.e. scientific, quantitative, separated from person or situation) but ultimately require a personal, non-value-free response. Health care workers can only help to find this response when they accept that the information they give is not neutral. Value neutrality therefore seems not only impossible to achieve, but is not even desirable.

Pitfalls in (re)presenting information

With regard to the counselling process, 'non-directiveness' is generally cited as the ideal. But what does it mean? We can explore the meaning by pointing out some main pitfalls in counselling. The above-mentioned observations about the context-relative and person-relative character of information provide the basis for what follows.

First of all, health care professionals are not justified in providing directive counselling if it means presenting facts in a one-sided, selective way, and therefore (intentionally or otherwise) underexposing some options while favouring others. The issue is not that counsellors should be non-directive, or that information should be presented impartially or in a value neutral way. Presenting all options as equally good alternatives ignores the fact that, often, some options are simply better than others, and there is no good reason not to say so. Information should be truthful, not distorted by personal prejudice or professional preference. The option, for instance, of early, pre-emptive transplantation (i.e. before a patient starts dialysis) has many advantages over transplantation later on. Counsellors who do not inform their patients about this fact are providing biased information and are making a serious mistake. But, at the same time, they should acknowledge that all information contains values. Professionals should try to deal transparently and communicate these values openly. Counsellors, if they endeavour to provide truthful information, are more likely to be viewed as trustworthy.

Secondly, health care professionals are not justified in providing directive counselling if they focus predominantly on the medical perspective, consider this perspective to be the 'most reasonable' and are blind to other perspectives. From the patient's perspective, considerations other than purely medical ones may be highly relevant as well; for example his/her relationship to the donor, his/her social network, etc. Living transplantation may, for instance, be 'better' than cadaveric transplantation for a number of medical reasons, but it is not self-evident that this medical perspective should be given more weight than other, i.e. ethical, social, psychological, perspectives. Conversely, it would be equally mistaken to suggest that a donor who is overweight does not represent a greater risk. Again, the issues here are not non-directiveness and value neutrality, but rather the fair portrayal and explanation of the different ways of evaluating and weighing these options.

We suggest that no one single objective description of 'reality' will suffice. The presentation of 'the facts' should provide patients and their relatives with the tools to decide for themselves what they think is best. It should be acknowledged that the assessment of all information is ultimately a personal one, in which the perspective of the donor or recipient is decisive.

Thirdly, it would not be justified to provide directive counselling by approaching potential donors as merely a means to an end, instead of showing them the respect they deserve. It would be mistaken to argue that saving the life of a patient (or relative) outweighs the relatively small risks and disadvantages for the donor, because this view overlooks alternative options *and* does not take account of other viewpoints and considerations. Respect for patients and their relatives implies that relatives will be contacted if, and only if, patients give their consent. Moreover, if health care professionals are viewed as the advocates of their patients, other advocates should also be appointed to defend and to protect the interests of the (potential) donors. In general, people can have reasons of their own, by referring to the particularities of their situation (Sie et al., 2004). Potential donors as well may have their own good reasons for not donating an organ. Professionals should help donors to express their perspectives, considerations and convictions. It should not be forgotten that donors also have families and lives of their own. For example, they may have doubts about the health risks involved in donation, uncertainty about their social situation, anxiety concerning the implications for personal relationships, duties towards others such as a partner or children, loyalties with regard to their occupation, or other commitments. Many of these concerns will be valid and should be taken seriously.

Justified interference: issues to be solved

Within those constraints noted in sections 4a and 4b, however, there is room for justified intervention. We have found, quite surprisingly, that, when asked, more than 50% of the patients and their relatives waiting for a kidney are open to the idea that doctors, (with the patient's consent) should address relatives directly. Some patients feel confused and threatened by the situation in which they find themselves. It is hard to imagine how these patients are able to ask a relative to donate a kidney. Many patients are afraid their relatives will refuse, but mask their fear and find reasons not to ask them to donate ("Given her situation, my friend should not donate") or not to accept any possible future offer ("I am not prepared to live at the expense of others"). Psychological and ethical issues are intertwined. This situation may be an appropriate opportunity to interfere, as health care professionals may be able to help the patient find a way out of this predicament. They can help patients to distinguish reality from imagination, and to disentwine their psychological defence mechanisms from their true personal needs and moral considerations. The counsellor, for example, might ask the patient: "How can you be so sure that he doesn't want to donate if you haven't discussed it?", or "Why don't you give your friends the opportunity to decide for themselves whether they wish to become your donor?", or even "Why don't you give your son the opportunity to help you?".

Given the apparent scope for justified intervention, however, some important issues remain to be solved.

First of all, should the patient's doctor (or any doctor) take the initiative to contact relatives, or are other professionals, such as psychologists or social workers, in a better position to do so? And should we find these experts within or outside the transplantation centres? Much depends on the emphasis one wants to put on the medical perspective, and the faith one has in doctors. And what role can patient organizations have in empowering patients and their relatives?

Secondly, what exactly should be the role of experts or support groups: to mediate between patient and potential donors, or to represent either the patient or the potential donor? To provide basic information, to offer counselling in a particular situation, or to refer to other experts for decision-making (through mediation, pastoral counselling, etc.)?

Thirdly, a health care professional must provide support for patients and their potential donors in light of their distinct needs. The interests of patients and their donor-relatives do not necessarily coincide, and may even be at odds. In a transplantation program it is important to decide at what point in the counselling process we should consider a patient and his/her relative(s) as a single unit, and at what point we should treat them as individuals with their own personal needs and wishes. If we assume that each relationship has its own unique characteristics, and that interests can overlap, it is far from self-evident where the interests of one individual end and the interests of the other begin. It seems that this not only requires clear and formal safeguards (e.g. by assigning potential donors their own personal health advocate), but also sensitivity to the fundamental needs of both parties on the part of health care professionals.

This is not just a practical issue. We believe that the impact of transplantation on close relationships requires more conceptual clarification. Patient and donor may, as we have said before, have strong common interests. There are disadvantages (health risks) for the donor, but also benefits from the transplantation. For example, transplantation may relieve donors of the burden of caring for the patient, they may regain a healthy partner, have better prospects of a future with their relative, or it may give them the feeling that they are being altruistic, etc. Yet this raises questions to which there are no easy answers. Should donors feel a duty to donate? Should donors also have benefits, and if no such benefits are present, should their offer to donate be refused? Or should donors accept at least some form of payment? Should a donation be based on altruism, or does the principle of reciprocity offer more solid moral ground? Or is a motivation based on the donor's self-interest the better option? Should one say that, in general, the overall benefits for a patient outweigh the harm to the donor and his/her family, as is claimed for cadaveric donation? Another pitfall of counselling assumes that one simple unequivocal answer can be appropriate for these complex questions – that there is a monolithic view available concerning morality and personal relations. As we will show, unique relationships and particular situations require their own answers. In explaining this, we will refer in what follows to the structure of fundamental beliefs and personal convictions, and conclude that general ethical concepts cannot fully account for the richness of moral experience.

Interference in fundamental beliefs

The structure of fundamental beliefs and personal convictions can be pictured in accordance with a number of models. Here we describe three such models, referring to well-known theories by Stephen Toulmin, John Rawls and Thomas Nagel, and ask whether interference in fundamental beliefs and personal convictions can be justified. We use these models in an heuristic way. All three represent ways of moral reasoning that exist alongside each other in everyday life, and can help counsellors to be sensitive to the strengths and weaknesses of these beliefs and convictions.

A deductive model

In a deductive model, as described by Stephen Toulmin, a conviction can be represented by a general principle or axiom that is applied in a particular situation. We may expect the logic of reason also to be valid for ethics (Baier, 1966; Toulmin et al., 1979). For example:

Principle: "One should not cut in a healthy body"
Fact: "In transplantation surgery – as well as in cosmetic surgery – one has to cut in a body that is healthy"
Inference: "Therefore, I reject this surgery"

This logical conclusion is not as strong and stable as it seems, and this belief (axiom) less deep and fundamental than one might think at first sight. Often people will be prepared to adjust their views, for various reasons, and in a number of ways:

- by qualifying the fact, e.g. "Kidney transplantation is a necessity, cosmetic surgery is merely a luxury, and sterilization is sometimes a good option."
- by limiting the principle, or its sphere of influence "One should never cut in a healthy body, unless something good can be accomplished by it."
- by specifying the conclusion "If the benefits outweigh the disadvantages, I can accept organ transplantation."
- by introducing or referring to another fundamental principle: "the principle of beneficence for me has priority over the principle of bodily integrity; this principle of charity should be ultimately decisive."

The insight which this model gives provides us with a justification for intervention: beliefs are not fixed, but dynamic, and should not be taken at face value. Interferences can contribute by helping patients and their relatives to refine the argument and give their views a more strong and stable character.

A network model

The network theory, borrowed from John Rawls, holds the view that the basis of our moral beliefs is not founded on fixed and solid ground. Instead of searching for ultimate principles or fundamental axioms, we should look at moral justification in a different way. The concept of coherence can explain how a moral point of view is comprised of various parts. Each view consists of a great number of ingredients: innumerable and very diverse facts, ethical principles, moral intuitions, experiences, values, considerations, etc. When we try to take a stand, what we usually do in everyday life is look for sufficient (internal) coherence (Rawls, 1971; Van der Burg and Van Willigenburg, 1998). For example, a patient says "*I would happily accept a kidney from my partner (unfortunately he does not match), but not from my daughter. I could live with the small risk for my spouse, as with other risks in life, like his mountaineering, but not with the risks for my daughter. At this moment we are happy with my dialysis and my nephrologist is content with how things are going.*"

In everyday life, we try to bring the various considerations together and obtain a more or less coherent picture of our situation. Considerations back each other up and strengthen one another mutually. This coherence is shaped in a dynamic, reflective process, in which facts are qualified, principles are limited and positioned vis-à-vis each other, moral intuitions are reconsidered, and provisional conclusions are specified. The aim is to give fair consideration to as many elements as possible. One can refer here to a "reflective equilibrium". An initial preference may be replaced after reflection by a more stable, well-considered judgement. In this process, (even) fundamental convictions are open to change. The example above may continue as follows:

- *initial preference*: "We appreciate dialysis at home (because my partner's kidney does not match)."
- *new fact*: "Our doctor has told us that we can take part in a cross-over programme."
- *moral intuition*: "I find it hard to accept the idea of receiving a kidney from a stranger, with its potential, unknown risk."
- *basic value*: "My partner, who is a doctor, is prepared to donate cross-over; he wants me to have confidence in this programme."
- *experience*: "I am, however, afraid of disappointment and do not want to cross this barrier; moreover, I have heard that blood group 0-patients, like myself, do not match very well and have little chance of successfully receiving a kidney transplantation."
- *new fact*: "My sister-in-law said at a birthday party that she was willing to donate a kidney to me. However, I'm not sure how serious she was in saying this; she had already had a few drinks."
- *moral intuition*: "I think that I would prefer a kidney from my sister-in-law."
- *new fact*: "My son has found a reliable address abroad where one can get a kidney from a stranger in exchange for money; we have the money, and this would at least eliminate the risk for my partner."
- *moral intuition*: "If I accept a kidney from a stranger, I would prefer this to cross-over."
- *well-considered judgement*: "So far, my experience with dialysis is fine and I consider cross-over to be taking things one step too far. I will wait to see what the future brings. My daughter has two young children who need their mother, my son has his own small business to run, and my relationship with my daughter-in-law has never been perfect. I'm reluctant to talk to my sister-in-law about her offer, maybe it's better to wait and see whether she brings it up again. My son is probably right that the better option can be found abroad. At the moment, all is going well, we should leave it as it is."

This personal judgement is provisional, but well-considered. It is the temporal close of a reflective process that never ends, as it is open to new facts and circumstances. For now it has balanced the various options.

This second model also provides a justification for intervention. Counsellors can see it as their role to keep the communication with patients and their relatives open. They can look for elements that can be reconsidered and take the initiative to open the discussion about these elements. They can try to give their support, if requested, in instances where facts are biased, views distorted, certain perspectives underestimated, and where room exists for new considerations. The network model can account for the dynamics of moral beliefs and the process character of moral reflection. It may help to understand the counselling process as a truly reflective process.

An agent-relative model

In the third model it is emphasized, for instance by Nagel (1986), that particularistic values also play a part in everyday morality, in addition to general ethical premises and principles. Individuals often have (good) reasons of their own, reasons that are highly personal in nature. These reasons reflect unique situations and personal commitments. They are by definition partial, in the sense that not every perspective is given impartial weight. Partial considerations can make up the core argument in moral judgements (Hooker and Little, 2003). They can bear significant weight. Take expressions such as "*I choose to donate just because* ...":

- *"I love her."*
- *"he is my mate."*
- *" her life is the only thing that matters to me."*
- *"I would never forgive myself if I didn't donate to my sister".*

Or, "*I choose not to donate because*" ...:

- *"I have responsibilities towards my little son, who is totally dependent on me"*
- *"I have duties towards the people I have employed in my new business."*
- *"I live for my professional career (Olympic synchronic swimming)."*
- *"I think my niece is in a much better position to donate."*

These arguments can be called 'person-relative', because they are in a unique way connected to the person who utters them. Various websites recall these unique stories (http://www.livingdonors.org). They do not express general moral truths, applicable to all others in the same situation, but a reality that is only true for the person concerned. Interestingly, particular features of the situation turn out to be morally significant. Significant for this person (actor, 'agent') are loyalties to particular individuals, commitments to certain personal projects or ideals, or coincidental circumstances, like the existence of a vulnerable niece.

This 'agent'-relative model seems to govern the morality of personal relationships and is highly relevant in the context of kidney disease. The strong appeal to potential donors who live in a patients' surroundings induces unique personal responses. Agent-relative considerations, more than all others, seem particularly decisive. A general rule like "*One should not let one's soul mate die*" or *"Partners have caring duties towards each other, as part of their marital bond"* is not the leading principle, but personal commitments and loyalties such as "*As far as I am concerned, I will not let my partner down*". Thus a general principle of *beneficence* (doing well) or *maleficence* (doing harm) is not applied, but a particular moral point of view is expressed, based on a highly personal ideal about what constitutes the particular good. Donors may refer either to what is perceived as good for a sick relative, or to the donor's own moral self-image, or to the unique relationship with the recipient.

To be able to understand someone's choice, health care professionals need to understand these ideals and the commitments and loyalties they represent. It may seem that these agent-relative views are less open to change and that counsellors can do nothing but simply comply with them. Does this imply that interventions are not justified within this model? To draw such a conclusion would be to misunderstand the agent-relative perspective. Agent-relative reasons are embedded in views about personal and moral identity (Hooker and Little, 2003; Sie et al., 2004) and therefore have their own justification. This identity is not something fixed and closed to all consideration. The justification of a position commonly takes the form of a narrative, a personal story, that can be more or less coherent and constant over time. Counsellors can take part in the shaping of this story, and in the identity formation of a patient or donor struggling with living transplantation (if, of course, the patient or donor wants such help and is open to it). An open discussion pays in fact tribute to the autonomy of agents. Agents, capable to consider reasonable arguments and willing to reconsider their views, will emerge stronger than before.

Counselling: inadequate concepts, but open minds

The agent-relative model can explain why many general ethical concepts – commonly used without much thought – are inadequate. In the context of personal relations, these concepts seem to lose their unambiguous, self-evident, ordinary meaning. This is true even for core concepts. What precisely is meant by a "free choice for living donation", a "voluntary decision", "an option worth considering", a "moral duty", an "altruistic gift", a "natural and self-evident act", a "reciprocal transaction", a "motivation based on self-interest", etc? In this context, it seems, a very different moral logic applies. Take a mother who can save her child's life by donating part of her liver. What do we mean when we stipulate that hers must be a free, voluntary gift? However ambiguous it may be, this is something health care professionals should ascertain. Interestingly, in everyday life we find a moral language that is necessarily ambivalent. The sense that neither of the characterizations mentioned above (free choice, self-evident act, moral duty, reciprocity, etc.) is entirely adequate is due to the fact that our minds and moral experience are open to the many particularities of a situation. Our prevailing general concepts cannot fully account for this. In people's utterances we can detect moral intuitions that are authentic and double-edged at the same time:

- A parent: *"I felt I had no choice, but it gave me a good feeling that I could donate and help my child; I took responsibility; I didn't feel like a victim of the situation; I took an active part in the process."*
- A friend: *"Of course, one has the choice, whether or not to donate; but I would not have forgiven myself if I had not done it; it was an inevitable duty."*
- A sister: *"It is only natural to help; this is simply what you do. I did not give it much thought. It has nothing to do with duties."*
- A child: *"It's both free and not free; she would have done it – reciprocally – for me."*
- A partner: "*Is it altruism? I don't know; I do it for him, and I do it for myself. It's easier to live with a healthy spouse than with a sick one; it's good for us both.*"
- A doctor: "*We should do this for each other, when risks are low. I believe that ethics demands that we consider it as a deadly serious option.*"
- A son: *"I would help my father. Fortunately, I have never had to consider donating a kidney seriously, because he doesn't want to talk about it."*

These views suggest that there are many ways to refer to what is morally at stake. It would be a mistake to think that ethics can and should be combined in one unambiguous language. This would reduce the richness of moral life (Cunningham, 2001).

The third model not only opens our eyes to this richness, (the second model does this, too), but also distinguishes between an internal and external moral perspective. Whereas the external perspective applies to general concepts, the internal perspective is more sensitive to the particular morally significant features of a situation. Both can differ considerably, and cannot easily be reconciled. Without going into the precise relationship that both perspectives should have with each other, we can reasonably conclude that general principles or social norms cannot give a full and adequate description, but should at least be augmented by more particularistic, personal pictures of the moral reality. Counsellors should therefore be open to these particularities of a situation, and sensitive enough to appreciate their moral weight.

Conclusion

We have argued that interference in peoples' personal lives is justified – if not obligatory. This interference, however, can easily become unjustified pressure. We have shown, first of all, that prevailing concepts in counselling, i.e. value neutrality and non-directiveness – given the pitfalls they imply – cannot account for the complex reality of living donation and transplantation and have only limited value as guiding principles in living organ donation. What is required instead is truthful information and counsellors people can trust. In addition, adequate information and effective counselling should be context- and person-relative, in order to respect the particularities of each case.

Secondly, we have shown that interference with personal belief systems can be justified. Views are open to change and can, accordingly, be influenced. Ethical theories account for this dynamic reality in different ways. They can help to discern between justified and unjustified interference.

We recommend a heuristic use of the models offered. A patient's personal view or belief may be better represented by one model than by another. A sensitive counsellor can make use of this insight and look for the model's potential openness for change (Toulmin), and for deliberation (Rawls). It might seem that Nagel's model is less open to external consideration, but this does not mean that counsellors have no role in the matter. They can support patients, if they wish, in their shaping of a personal story and in their (dynamic) identity formation. Nagel's representation of the particularistic position takes into account the richness of moral reality, and suggests that health care professionals should not reduce moral language to the general ethical concepts that often prevail but be sensitive to the particularities of a situation and appreciate their moral weight.

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