

## *Lost in Translation*

### *Cultural Obstructions Impede Living Kidney Donation among Minority Ethnic Patients*

ANNE HAMBRO ALNAES

After several months of anthropological fieldwork studying living kidney donation (LKD) decisions, I was surprised how rarely patients of non-Western background appeared to have a relative willing to donate a kidney.<sup>1</sup> If this indeed is the case, what are the reasons behind this imbalance? A patient with a familial kidney donor usually undergoes transplantation surgery within a few months.<sup>2</sup> Waiting for a deceased-donor (DD) kidney takes a longer time. The tissue match is often inferior compared to when the donor is a close relative, resulting in shorter graft survival. Based on findings in my fieldwork, it would seem that culturally based obstacles trump medical common sense when non-Western patients decide against LKD.

For the discussion that follows, I have selected 2 cases from my sample of 18 LKD cases from fieldwork (2008–2011) conducted at four hospitals in the greater Oslo area in Norway: one, a 45-year-old woman from Pakistan (the largest non-Western minority group in Norway); the other, a patient originating from an African country. The former had several hypothetical donors, whom the nephrologist discounted for a variety of sociomedical reasons. The latter had four close blood relatives living in Norway, none of whom responded, despite the nephrologist's repeated letters to discuss the possibility of LKD. Both patients ended up receiving a DD kidney.

The cases may be critiqued for being too particularistic to provide general knowledge about why LKD is rare among families with Asian or African backgrounds. However, some of the reasoning I encountered has the potential to alert healthcare teams about unforeseen cognitive and emotional obstacles and misunderstandings. Several of these constraints may turn out to be modifiable, but only if they are taken seriously and addressed, not simply dismissed as communicative "noise" caused by superstition, ignorance, and misinformed cultural preunderstandings.

First, a few words are in order about the Pakistani community and their relatively greater need for renal replacement therapy (RRT) compared to ethnic Norwegians. The prevalence of type 2 diabetes (T2D) among Pakistani women aged 30–67 is 14 times higher than among ethnic Norwegian women.<sup>3,4</sup> Reports from the UK indicate that East Asian T2D patients develop end-stage renal disease three to four

---

This article has been written with support from the Foundation for Health and Rehabilitation. I wish to thank the donors and recipients, the nephrologists at the four hospitals where I conducted fieldwork, and my husband, Egil Alnaes, Ph.D., for his suggestions and patient proofreading.

times more often than majority population patients,<sup>5,6</sup> a tendency that is likely to prevail also in Norway. Living donation is generally considered to provide better and longer-lasting results. Yet in Norway, patients of Pakistani and other non-Western origin apparently prefer to wait for a kidney from a DD. This indicates either that minority migrant patients do not see the advantages to living donation, as explained to them by the nephrologist, or that removing and transferring a kidney between family members is thwarted by cultural misgivings. There are no exact numbers as yet to statistically document the relative rareness of LKD among non-Western migrants in Norway, but such tendencies have been confirmed in the UK, for example.<sup>7</sup>

How can this disparity be accounted for? Do migrant minority patients distrust the healthcare system, which appears to expect that they further their own cure by providing a close family volunteer? Perhaps some patients suspect that when the doctor asks for a next-of-kin list she or he is actually trying to cheat them out of a valuable “good”—DD—kidney to which ethnic Norwegians are entitled? Statistics Norway, however, maintains that few in the Pakistani minority harbor distrust toward the healthcare system.<sup>8</sup>

Can skepticism toward LKD be explained by economic reasons? Considering that kidney transplantations are free of charge, that the healthcare system covers the (considerable) costs of lifelong immunosuppressive therapy, and that the potential donor receives compensation for lost wages in connection with nephrectomy, this hardly seems likely.

As I met and listened to non-Western patients undergoing dialysis, heard their relatives' accounts, and read the medical records, I started suspecting that both doctors' and patients' communicatory competence<sup>9</sup> needed to be seriously questioned. Do non-Western patients understand what they consent to, or what they deselect, when they choose to *not* inform relatives about their need for renal replacement therapy and the possibilities of LKD? And do the nephrologists provide patients with enough information and access to sources of evidence to ensure that their patients absorb and are able to implement such information in order to make a reasoned decision?

In LKD situations, the term “informed consent” is significantly more complex compared to other medical interventions. Some analysts dismiss the current practice of informed consent as little more than protection against possible litigation and compensation claims, the equivalent of a “modern clinical ritual of trust.”<sup>10</sup> However, as O'Neill wryly comments, “there is disagreement both about its [the ritual's] real meaning and about its proper performance.”<sup>11</sup>

What sets LKD informed consent apart is that nephrectomy does not benefit the donor in any medical way. On the contrary, it inflicts physical harm and pain and therefore runs contrary to doctors' basic ethical principle of *primum nil nocere*. Nephrectomy can only be justified as a way of fulfilling the autonomy of a parent, spouse, or sibling who wishes, through donation, to heal a loved one. This inherent contradiction is in part disguised by organizing informed consent as a quasi ritual. Informing about the documented small risks of nephrectomy can be likened to the reassuring and anxiety-lowering aspects of certain other, nonmedical rituals.

O'Neill maintains that the point of consent procedures is to limit deception and coercion. However, although overt coercion is shunned in LKD explorations, the presence of symbolic violence, “that invisible power which can be exercised only

with the complicity of those who do not want to know that they are subject to it or even that they themselves exercise it,"<sup>12</sup> needs to be recognized. Presenting apparently neutral information about LKD to potential donors can imperceptibly morph into persuasion and slide into indirect coercion. Although it is always possible for donors to retract after signing the consent document, this nevertheless takes considerable courage.

The weight of providing comprehensive and relevant information does not lie only with the doctor who wholly depends on would-be donors' honest accounts of the reasons they wish to donate. Problems arise when the potential donor leaves out important clues, not only about his or her physical condition but also about possible emotional pressures, difficult family relationships, and past and present unresolved conflicts. Would-be donors sometimes think it wisest to leave out bits of information that might weaken their chances of passing the evaluating team's "exam." Deceit caused by strategic omission thus cannot be ruled out. Although tools have been developed to gauge patients' competence in decisionmaking (ACE<sup>13</sup> or MacCat<sup>14</sup>), for instance by including feedback loops about whether the information has been understood, these checklists are arguably less suitable for judging whether a person is in his or her right mind to donate a body part, a decision reflecting moral obligations and notions of family solidarity.

Consent in LKD situations flows in both directions. It presupposes the doctor informing about and the patient consenting to medical treatment. But more is involved. The doctor not only has to rule out medical counterindications. She or he also has to approve of and grant the donor's request, that is, the doctor must consent to letting a patient irrevocably part with a healthy body part to help a relative. By consenting, the doctor justifies a donor's physical loss by his or her emotional gain and satisfaction of helping and saving a loved one.

Communicatory competence in LKD situations entails that the nephrologist listen actively and encourage both patient and potential donors to engage in dialogue with him or her about the pros and cons of living donation. The nephrologist should be actively on the lookout and attempt to redress possible misconceptions that may be rooted in linguistic insufficiency or cultural preunderstandings. Several of the non-Western kidney patients I met appeared to be fluent in Norwegian. However, talking with them in the informal atmosphere of their homes, I discovered that they were often unable to relate to elementary medical terms. Preventable and curable diseases were sometimes spoken about as fate or punishment for some wrongdoing. Explaining diseases like T2D or kidney failure by pointing to influences from society, God, or supernatural powers constitutes a way of reducing the patient's personal responsibility to attend regular health checks and to follow the doctor's advice on changing lifestyle and diet. Ideally, the nephrologist should help empower patients to improve and if possible control their own health status.

### **Case 1**

"Olivier," a Norwegian citizen of African descent brought up as a Roman Catholic, fluent in Norwegian, and married to a well-educated Norwegian woman, has lived in Norway for the past 20 years. He had never come in for a medical checkup and did not even know the name of his primary care physician with whom he had been

registered by the health authorities. He had for some time been plagued by severe headaches, but it was only after visiting an optician to get a stronger prescription for his glasses that Olivier's high intraocular pressure was discovered. A few days later he was admitted as an emergency patient with acute kidney failure.

Being otherwise in good physical shape, Olivier recounted how he had been totally unprepared for the dramatic hour-by-hour surveillance he was subjected to when admitted to the hospital. He claimed that the doctors never had time to speak to him and explain his diagnosis, although according to the medical records his nephrologists had informed Olivier about LKD and DD donation within weeks after starting dialysis. Following normal procedure, the nephrologist asked Olivier for a list of his "closest" family to explore the possibility of LKD. After it became clear that two of Olivier's brothers and two cousins had immigrated to Norway, the nephrologist had reasonable hopes that a donor would be found.

Olivier recounted his instinctive reservations about supplying such a list: this approach constituted an improper transgression of his culture's rules of hierarchy, which state that the eldest of the family must be informed first, before others become involved. Moreover,

it would be unseemly for them to get to know about my illness through an intermediary like the doctor. My brothers and cousins know my health is precarious; they also have been told that two of my siblings back home [i.e., in Africa] have offered to donate. But donors from far-off countries, like mine, are not accepted in Norway. I don't want to ask my brothers and cousins for a kidney, it is up to them to volunteer.

Olivier's wife (a potential emotional-kin donor) told me that that she had not been called in by the nephrologist to discuss the possibilities of donating. Nor had Olivier told her he did not wish her to donate. She had, however, of her own accord, undergone a blood test that proved that she was incompatible. Unwilling to give up hope of a family volunteer, she repeatedly tried to explain Olivier's urgent need for a kidney to her (African) brothers-in-law, in non-"medicalese" language, convinced that one of them would finally volunteer. "I felt like a beggar," she recalled. Nine months later, neither his brothers nor his cousins had responded to the nephrologist's letters containing unambiguous information about Olivier's life-threatening condition. As he never received any response from them, the doctor concluded it would be unethical to pursue the donation issue further, and Olivier was placed on the DD waiting list. In the course of conversations with him, sensing that Olivier was deeply embarrassed about his brothers' unwillingness to donate, I changed the subject.

I later learned (not from Olivier) that a person in his wife's family had secretly undergone medical evaluation to qualify as a donor. However, just before the potential donor's medical workup was completed, Olivier was offered a DD kidney, obviating the in-law's offer.

After Olivier had undergone transplantation, I tried to find out how his brothers had reacted to and understood the evaluation process. (I was only given access to one of his brothers.) In as roundabout a way as possible I tried to fathom whether he experienced regrets. Alternatively, had the routines followed by Norwegian nephrologists simply misfired when used to approach Olivier's brothers and cousins? Were the letters too indirect to invoke the response the nephrologist

had counted on? In my conversations with the brother I was permitted to meet, I heard no traces of guilt. On the contrary, he told me how he had helped boost his morale and recalled, with admiration, how Olivier, as a result, had continued to work in his physically demanding job, only taking short breaks to undergo peritoneal dialysis. Moreover, as Oliver was no longer at the hospital, Olivier's brother concluded that the nephrologist's letters had exaggerated his condition. He was in "the best possible hands," and there could be no hurry or need to respond to the nephrologist's letter. "If it was that serious," this brother queried, "why did the doctor never call us in to talk about possible donation?" I concluded that despite Olivier being on dialysis, neither his brothers nor his cousins seemed to have grasped how urgently Olivier needed a kidney.

## Case 2

"Sofia," a South Asian 45-year-old divorced mother of three, had been placed on dialysis due to (nondiabetic) kidney failure following 13 years of treatment. Like Olivier, she was fairly fluent in Norwegian and held a regular job. Sofia's case was unusual: her ex-husband, a niece, a nephew, and a close friend (only the last candidate is mentioned in the medical records) were all willing to donate. Sofia told me that her nephrologist discounted her ex-husband due to his "irregular" lifestyle. The 22-year-old niece was also ruled out (but is not mentioned in the medical records), as she would have to be temporarily "imported" from the Indian subcontinent for evaluation. However, as she would have to return to her home country, where appropriate postnephrectomy follow-up could not be guaranteed, this would be against Norwegian healthcare's mandatory obligations to donors.

Sofia herself refused the offer from her close friend, as the latter suffered from mild asthma and minor allergies. The remaining potential donor—her nephew—was a student in a neighboring country. He had recently married a fellow Southeast Asian girl living in Norway and was now applying for family reunification. If accepted, this meant he would have received postdonation care. However, his parents-in-law, as well as his wife, were against him donating a kidney. According to Sofia, they believed such surgery would compromise his sexual and reproductive potential. This excuse was evolved during only one of my conversations with Sofia and was thus not an argument that Sofia's nephrologist could have addressed and refuted.

When I visited her at the dialysis unit prior to transplantation, Sofia appeared worried about whether her religion was opposed to living donation. Indeed, she asked me whether there existed written documents on Islamic policy on this subject. As none of Sofia's four potential donors materialized, she was put on the waiting list for a DD kidney. She appeared comfortable about the prospect of receiving a kidney "from you," that is, referring to the pool of Norwegian, non-Muslim deceased donors.

After receiving a DD kidney, Sofia confided that she had considered traveling to her home country to purchase a kidney.

I didn't want to buy a kidney from a poverty-stricken vendor on the black market, which would have cost me \$4,000. Instead, I started planning how to arrange for a kidney transplant at a public hospital, which would cost \$30,000. This is of course far beyond what I can afford,

but I counted on the Norwegian Welfare State to subsidize my expenses. When I broached this possibility with my nephrologist, I was warned against the inferior medical standards in my home country. Fortunately, I was offered a kidney after less than two months on the waiting list.

I now turn to insight gained from three primary care physicians of Pakistani origin in Oslo. In conversations with them, I learned that none of them prepared their severely ill T2D patients for the unpleasantness and constraints of probable dialysis, by, for example, handing out the multilingual illustrated pamphlets (in Urdu, Arabic, English, and Norwegian) available since 2008. Nor did they inform their patients about the possibilities of LKD in case of possible kidney failure. Handing out such information, one of these Asian immigrant doctors maintained, is the responsibility of physicians at the nephrology ward, that is, after the patients' kidneys have reached their end stage.

A second (female) immigrant physician pointed to a reason against young people donating to a sibling or parent: if it becomes known that a prospective bride or groom only possesses one kidney, this reduces the chances of finding a suitable marriage partner. Seventy-five percent of all Pakistani marriages in Norway are "facilitated," with either the groom or the bride still living in Pakistan. This physician mentioned another more practical counterargument: many South Asians run small family businesses, and two to six months of sick leave for two family members (donor and recipient) may incur economic repercussions. Accepting a DD kidney, on the other hand, involves sick leave for only the recipient and is therefore seen as a lesser threat to the family's inclusive economic fitness. Thus, several duties need to be weighed against one another, usually rendering DD donation the better solution in their view.

The third Asian General Practitioner pointed out how ethnic Norwegian doctors seem unaware of the Indian/Pakistani culturally prescribed rules regarding whom to include and the appropriate channel to use when communicating information about health matters. Among South Asians it is expected that the whole family is included and consulted when the health of a family member is at stake. Sending a letter, that is, a bureaucratic document printed on hospital stationery, asking relatives to consider donating a kidney is regarded as totally out of step with the magnitude of the message's content. Moreover, there is no obligation for recipients to respond to such official letters signed by an unknown person. In contrast, according to South Asian codes of conduct, when doctors call in the patient *and* his or her family, this is interpreted as a sincere and proper way of showing concern and care. This GP also stressed the distinction between South Asians' understandings of patienthood versus the average Norwegian's approach. South Asian children and adult patients are taken to the doctor by their family, as opposed to Norwegian patients (except the very young and the aged), who make an appointment with their doctor as an autonomous individual. The South Asian family expects to be fully informed and is in turn counted on to care for the sick person. According to this GP, family members should be approached about LKD directly, that is, face to face, not indirectly through letters.

Several of these South Asian GPs' claims stand in contrast to the professional norms guiding ethnic Norwegian physicians. A doctor relates to an individual patient, not to his or her extended family. Sending an exploratory letter is meant to avoid being too direct and to give the addressees time to consider the doctor's information about alternative therapeutic possibilities. In spite of their neutral wording, the letters are not intended as bureaucratic sheets of information that

need not be answered. Despite these intentions, one nephrologist maintained that 50 percent of the letters he sent to relatives (both ethnic Norwegians and those with a minority background) of end-stage renal disease (ESRD) patients go unanswered, although some (ethnic Norwegians) do contact the doctor by telephone. This gives reason to question whether sending exploratory letters is the best approach to engage family members.

### **Communication Challenges in LKD Situations**

These two cases have several points in common. First, both Olivier and Sofia had potential donors in their family who for various reasons were not followed up on as possible donors. A second feature was the apparent lack of communicatory ease between the patient, his or her family, and the healthcare staff. Third, by comparing my own field notes with the medical records and conversations with the nephrologists, I discovered misinformed assumptions that could have been resolved if they had only come to light. Olivier's and Sofia's chances of receiving a LKD might have improved, and their time on dialysis might have been reduced.

Communication theory models (which are only superficially accounted for in this presentation) afford a useful tool for exploring how doctors handle the recruitment of donors. For doctors, comparing such models gives them a tool with which to reflect on which of the four prototypical patient-doctor role models (paternalistic, informative, interpretive, and deliberative) outlined by, for example, Emanuel<sup>15</sup> best meets the needs of non-Western patients.

Communication about LKD is triangular in that it involves separate meetings between the nephrologist, his or her patient, and a potential donor. For many patients, the realization that RRT can no longer be postponed is gradual. The topic may already have been discussed within the family, thereby mentally preparing the ground for one or several donors to volunteer without any prompting from the nephrologist. The situation is different when family members are dispersed and not in regular contact with one another. But here too, information is transmitted stepwise: first through a letter containing a précis of their relative's condition and therapeutic options, ending with a noncommittal suggestion that they go through a preliminary blood test to assess compatibility.

From conversations with nephrologists I understood that evaluating potential donors consisted of three differently directed obligations: first, to inform about possible peri- and postsurgery risks, pain, likely time of recovery, the chances of postsurgery depression, the advantages of living donation, and how to prepare for possible rejection episodes or graft loss in the recipient; second, to prescribe a number of medical tests to ensure that the donor's health is satisfactory; and third—the most challenging and least linked to medical evaluations—to scrutinize motivation and exclude the possibility that donation has been agreed to under pressure.

As regards the dissemination of information to potential donors, the nephrologists I spoke to—some of whom I myself witnessed in clinical situations—appeared to employ an equivalent of Shannon and Weaver's (1949) transmission model of communication. Their focus was on (1) how accurately signals are transmitted, (2) how precisely the words (or other symbols) convey the transmitter's meaning, and (3) how effectively the message makes the addressees behave according to the addresser's intentions. Interferences such as crackling on telephone lines or "snow"

on television screens, defined as “noise,” distorts or prevents the message from being decoded according to the addresser’s intentions.

Although this model was useful for mechanical media such as the telephone or radio, when applied to people communicating orally in, for example, doctors’ surgeries or hospital wards, Shannon and Weaver’s model is a gross oversimplification. For instance, it did not sufficiently recognize the relevance of context or that the encoder’s intentions may differ significantly from the decoder’s understanding of the message. Later communication studies have pointed out how decoders actively select, deconstruct, and interpret the addresser’s signals to render messages comprehensible for their own use. Gerber’s model (1956) showed how recipients adjust the content of a transmitter’s message’s (external) stimuli to fit in with their internalized concepts and needs seen through the lens of values and expectations formed by their cultural background. This suggests why the cultural preunderstandings that patients and doctors each bring to the consultation room are crucial ingredients for meaningful communication. Indeed, culturally based understandings such as the causes of disease or what patients expect from their doctor are not irrelevant “noise” but are rather a resource for developing active listening skills.

Applied to the clinical situation, in which doctors are accorded little time for each patient, transmission efficiency is of the essence. The nephrologist needs to know that the information he transmits to his patient is absorbed, which can be partially gauged by the degree to which a patient complies with medication regimes, or, in LKD-situations, fulfills the nephrologist’s request for a list of potential donors. Communication clearly consists not only of information stimuli and decoding but also of interaction, negotiation, and feedback loops. It also presupposes a degree of redundancy. By redundancy I refer to nonessential informational fillers, which, paradoxically, are essential for grasping the core essence of unexpected messages. Absorbing bad news and unexpected diagnoses is difficult for anyone, but for people with imperfect language skills, a higher amount of redundancy appears necessary.

For informed consent to be valid, a minimum of linguistic competence is obviously a precondition. Such elementary language skills are however unlikely to be sufficient for a seriously ill patient to absorb new and sometimes technologically advanced information. Calling in a professional interpreter may afford a strategy to further a shared understanding of what is at stake. But patients with minority backgrounds are known for not trusting interpreters’ confidentiality. An interpreter’s censoring presence may indeed achieve the opposite of what is intended: it may impede a patient or potential donor from expressing the intimate doubts, fears, and wishes necessary for reaching an informed decision. Patients’ insufficient language skills may thus have far-reaching effects on donors’ and recipients’ informed consent competence and yet may go unnoticed by the doctor.

## Discussion

In the first case study, Olivier had—according to his doctor—received ample information about his serious kidney condition. Yet he himself insisted that he had never been given a diagnosis. Considering the divergence between his and the nephrologist’s accounts, we can infer that Olivier’s emotionally chaotic experience had temporarily narrowed his comprehension horizon as regards



the nature and reasons for renal failure. Although doctor and patient spoke Norwegian during consultations, differences between Olivier's and the doctor's culturally informed preunderstandings regarding what, to whom, and when to transmit fateful information meant that they communicated according to different codes.

Olivier represented a formidable ethical challenge to his nephrologist. When Olivier procrastinated in supplying a list of relatives living in Norway, this could have been taken as an indirect signal that Olivier was against pursuing the living donation option. For, according to rules of autonomy, a patient need not agree to LKD even if the nephrologist believes he or she does not understand his or her own best interests. Not wanting to put close family under pressure or fear of incurring an unpayable debt may be underlying objections, although Olivier never cited these reasons. His (ethnic Norwegian) wife knew about the advantages of living donation and was convinced that one of her in-laws would volunteer. As events turned out, she had drawn a premature parallel between how ethnic Norwegians usually rise to the call when a close relative's life is at stake, and how she thought her husband's family would react.

However, as his letters were never answered, the nephrologist concluded that none of the brothers or cousins were sufficiently committed to the well-being of Olivier to consider donating a kidney. To therefore conclude that they lacked ordinary familial solidarity is perhaps premature. Rather, the content of the concept of solidarity needs to be delimited by culturally informed boundaries between morally obliging versus dishonorable behavior. Handing out substantial amounts of cash as presents when visiting one's family "back home," or sending money to cover healthcare costs (as Olivier's brothers had done in past years), constitutes an expected code of conduct. But donating a kidney—an act they had never heard that anyone within their cultural lifeworlds had done—in their view clearly did not belong within the category of family solidarity.

Continuing now to the second case, two issues merit further comment: First, Sofia had revealed an unexpected medical argument against LKD: the belief that removing a kidney endangers male donors' erectile and procreative potential. Sofia concluded that the sexual malfunction frequently known to affect men undergoing dialysis would also affect the sexual potential of healthy donors. This false analogy disregards evidenced-based information given to potential donors, namely that a person can lead a perfectly normal life after donating a kidney, because the remaining kidney after a while compensates for the removed kidney's function. In Sofia's case, the nephew never pursued his offer, and the nephrologist was thus not given the occasion to counter this misunderstanding. Just as interestingly, Sophia had heard rumors that donation might threaten a woman's childbearing potential, but she did not seem to regard this as sufficient reason for turning down her niece's offer to donate, which the Norwegian health authorities would not have accepted (as aforementioned).

Second, Sofia did not distinguish between (1) being reimbursed for surgery abroad when treatment in Norway is not available within officially set time limits and (2) surgery that depends on the sudden and unforeseeable death of a patient and the deceased's and/or next of kin's consent to donation. Sofia said she would not have accepted a kidney from a poverty-stricken Muslim vendor. But she closed her eyes about the source of the kidney she thought would be offered in her home country.

An important concern for Muslim immigrants when approached for organ donation (both LKD and DD donation) is the role of religion. Searching for an authoritative doctrine that is binding on all Islamic followers and that might be used in organ donation situations is futile, as, according to medical ethicist Farhat Moazam,<sup>16</sup> no single Islamic perspective exists.

During my fieldwork I only met with one Islamic donor-recipient couple—two siblings.<sup>17</sup> This donor maintained that living donation was in accord with her Muslim faith. In contrast, after death, the deceased's organs belong to Allah. They are no longer "giveable." One Muslim country, Pakistan, recently (2010) passed an act on the transplantation of organs and human tissues. Only living donation to and from close relatives is considered legal. The sale of kidneys is prohibited, although the practice exists clandestinely.

I now briefly return to the South Asian doctor's views about ways of expanding common ground between ethnic Norwegian nephrologists and non-Western minority patients in need of RRT. Her claim that South Asian patients and their families expect to be included in the same consultation, which would perhaps even comprise potential donors, is incompatible with the fundamental principles of confidence guiding ethnic Norwegian doctors' professional code: recipients and potential donors are supposed to be evaluated by different doctors who represent each person's not always coinciding interests. Second, discussing who might volunteer as a donor within earshot of the kidney-needing patient constitutes unthinkable and unethical pressure. Third, to prevent families from falling apart, Norwegian doctors feel obliged to spare their patients from learning about family members who do not wish to donate, and to relieve decliners' potential feelings of guilt. The doctor needs to retain the option of resorting to "compatibility problems" without giving detailed explanation.

Communication is not only about what transpires between people along different channels, and in different contexts. On a more comprehensive level, society has a moral obligation to provide and spread information and ensure that less-advantaged migrant minority groups possess access to healthcare that is equal to the majority population. If we are to gain systematic knowledge about the prevalence of diabetes, hypertension, and other diseases leading to kidney failure among migrant minorities and to better their chances of receiving therapy at an early stage, it is essential to identify and target such groups. Up to 2011, the patient's country of origin has not been reported in official health statistics or entered into medical records in the Norwegian healthcare system. The unofficial rule against registering such information has been justified by a fear of racism (although the police and Statistics Norway have for many years recorded people's country of origin in their records and publications).

In June 2011 the Norwegian Council for Quality Improvement and Priority Setting in Healthcare inaugurated a change in policy. The absence of information about patients' country of origin was redefined as a risk that immigrants might not be receiving health services of satisfactory quality. The council asked that requisite and relevant data should be made available from 2012, preferably from existing health registries. As all Norwegians are equipped with a personal identity number (Personnummer), it will be possible to cross-reference patients in different national health registers (such as the diabetes register established in 2006) with the National Population Register (Folkeregister) (in which country of origin is registered), thereby providing a reliable picture of the prevalence of

various diseases among diverse subpopulations within the now culturally plural Norwegian population. However, as these are sensitive data, researchers will not be able to trace the identity of individual patients, and such cross-reference studies will still depend on permission from regional ethics committees. The council's recommendation represents a promising and timely move to discover and treat diseases at an early stage and to promote greater equity.

## Conclusion

The two cases in my discussion epitomize how the two-way giving and receiving of information about unfamiliar and complicated medical interventions such as LKD is treacherous when transmitted across cultural fault lines. We have learned from whispering games, when information is relayed via several links, for instance, from doctor via the patient to the patient's family, what gets transmitted may be a distortion of what the doctor had intended. Losses in translation are further exacerbated when the messenger, here the anxious, kidney-needing patient, lacks medical insight and is formed by a worldview reflecting different values and different codes of conduct. As informed consent depends on a lack of coercion and deception, particular attention needs to be directed toward understanding cultural preunderstandings and the way they impinge on decisionmaking. Otherwise doctors may be deaf to patients' reasons for opting against recommended treatment, such as LKD. Greater donor willingness among non-Western migrants might ensue if doctors paid more attention to the culturally defined, different rules about whom to include when planning a patient's therapeutic prospects and how to impart information. Recruiting living donors from ethnic minorities without adjusting communication to be in tune with cultural norms and expectations is counterproductive and ethnocentric.

## Notes

1. Living donation rates in Norway (4.8 million) are among the highest in the world (36 per million in 2008). Most patients receive a kidney within one year on the deceased-donor waiting list. See Leivestad T. Annual report. *The Norwegian Renal Registry (Norsk Nefrologiregister)*. Oslo 2009.
2. See note 1, Leivestad 2009.
3. Jenum AK, Holme I, Graff-Iversen S, Birkeland KI. Ethnicity and sex are strong determinants of diabetes in an urban Western society: Implications for prevention. *Diabetologia* 2005 Mar;48(3):435–9.
4. Kumar B, Grøtvedt HE Meyer, Sogaard AJ, Strand BH. The Oslo Health Immigrant Profile. Report from Folkehelseinstituttet 2008:7
5. Randhawa G. Renal health disparities in the United Kingdom: A focus on ethnicity. *Seminars in Nephrology* 2010;30(1):8–11.
6. Burden AC, McNally PG, Feehally J, Walls J. Increased incidence of end-stage renal failure secondary to diabetes mellitus in Asian ethnic groups in the United Kingdom. *Diabetic Medicine* 1992 Aug–Sep;9(7):641–5.
7. Randhawa G. Organ donation and transplantation: The realities for minority ethnic groups in the UK. In: Weimar W, Bos B, Buschback JJ, eds. *Organ Transplantation: Ethical, Legal and Psychosocial Aspects Towards a Common European Policy*. Lengerich: Pabst; 2008.
8. Blom S. Innvandereres helse 2005/2006. Statistics Norway; 2008.
9. Hymes, Dell. On communicative competence. In: Duranti A, ed. *Linguistic Anthropology: A Reader*. Oxford: Blackwell 2001.
10. Faden RR, Beauchamp TL, King NMP. *A History and Theory of Informed Consent*. New York: Oxford University Press; 1986.

11. O'Neill O. Some limits of informed consent. *Journal of Medical Ethics* 2003 Feb 1;29(1):4–7, at 4.
12. Bourdieu P, Thompson JB. *Language and Symbolic Power*. (trans. G Raymond, M Adamson). Cambridge: Polity Press; 1991, at 164.
13. Aid to Capacity Evaluation (ACE); see <http://www.utoronto.ca/jcb/disclaimers/ace.htm>.
14. Grisso T, Appelbaum PS, Hill-Fotouhi C. The MacCAT-T: A clinical tool to assess patients' capacities to make treatment decisions. *Psychiatric Services* 1997 Nov;48(11):1415–9.
15. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA* 1992 Apr 22/29;267(16):2221–6.
16. Moazam F. *Bioethics and Organ Transplantation in a Muslim Society*. Bloomington and Indianapolis: Indiana University Press; 2006.
17. Alnaes AH. Narratives: An essential tool for evaluating living kidney donations. *Medicine Health Care and Philosophy* 2012;15(2):181–94.