

Concealed by the “Gift of Life”

The Complexities of Living with Dialysis
and Kidney Transplantation in Stockholm and Riga

MARTIN GUNNARSON

INTRODUCTION

In this chapter I view kidney transplantation from the perspective of hemodialysis. Or more specifically, from the perspective of persons who have been transplanted on one or more occasions and are now back on dialysis. Transplantation and dialysis are the two treatment alternatives available for persons diagnosed with end stage renal disease or, in lay terms, kidney failure. The diagnosis pertains to the incapacity of the kidneys to free the blood from toxins and excess fluid. If it is not treated, the outcome is fatal.

There are two types of dialysis treatment: hemodialysis and peritoneal dialysis. Hemodialysis is the more common of the two and thus the focus of my study.¹ In hemodialysis the patient’s blood is circulated through a dialysis machine that rids the blood of its toxins. This process ordinarily takes four to five hours and needs to be repeated three times a week. Typically, the treatment is carried out at a hospital unit. Depending on age and overall health conditions, a patient’s life can be sustained for several years on dialysis.

There are two ways in which kidney failure patients may receive a transplant: from a living or from a deceased donor. In most countries living donors are related or in other ways emotionally attached to the recipient. However, during recent years live donations from unrelated donors have become more common. If no suitable living donors are found, or if the potential recipient is unwilling to accept an organ from a living person, deceased donation is the alternative. But the waiting list for deceased donation is long in most countries, and while waiting, the kidney failure patient needs to undergo dialysis.

Today, the problem of a shortage of organs dominates the global debate on organ transplantation (Siminoff and Chillag 1999, 34). The reason people die on waiting lists, it is said, is because not enough people are willing to donate (Lock and Nguyen 2010, 234–36). This notion rests on an understanding of transplantation as a routine lifesaving therapy. The problem haunting the transplant industry is the shortage of organs available for transplant, not disproportionate medical risks (Omar, Tufveson, and Welin 2010, 86). As a result, the act of donation has been framed within the powerful metaphor of the “gift of life.” By the use of this metaphor, the gap between filling out a donor card and saving the life of another person is narrowed and the presence of brain death, transplantation coordination, and organ rejection is under-communicated. In this “mechanistic image ... [transplantation] is often imagined to restore health in a fairly straightforward way, analogous to replacing a faulty motor part” (Crowley-Matoka 2005, 821). Here, a second promise of organ transplantation emerges: not only does it

save lives, but it also restores health. As a parallel process to the body's regaining a lost function, the recipient of an organ regains his or her lost life. Framed in this manner, the risks that accompany transplantation, the hardships of living with a transplant, and the ever-present possibility that the organ will cease to function tend to be relegated to the background (Crowley-Matoka 2005; Sharp 2006, 110–23; Siminoff and Chillag 1999).

Since there is dialysis, kidney transplantation is not as acutely lifesaving as, for instance, heart, lung, or liver transplantation. There is almost always a possibility to return to dialysis. Still, in the public discussion, kidney donation and transplantation is included in the shortage debate and the "gift of life" metaphor. First, this has to do with the conception of donation as a single act. In the promotion of organ donation, the symbolic power of the lifesaving capacity of transplantation is applied to the "gift of life" as a whole and not to the specific organs that are given. Second, when remedies to the problem of the organ shortage are debated, the superior survival rate and quality of life of persons living with a functioning transplant as opposed to those living with dialysis are invoked. Here, the suffering and dying of dialysis patients is used as a point of departure for further argumentation on how to solve the organ shortage. This results in a rather one-sided image of the lives of both dialysis patients and transplant recipients in which the two treatment alternatives become each other's opposites. In this imagining, transplant recipients are portrayed as once-and-for-all saved and capable of returning to a healthy and normal life, while life with dialysis becomes almost incon-

ceivable, since it is reduced to mere waiting, suffering, and dying (see, e.g., Abouna 2008, 34; Charro et al. 2008; Matas 2008a, 2008b; Monaco 2007; Omar, Tufveson, and Welin 2010, 94; Radcliffe-Richards et al. 1998; see Iddvall 2007a).

In this chapter I wish to nuance this one-sided image. I aim to unsettle the conception of life with dialysis as mere waiting, suffering, and dying and life with a functioning transplant as a return once and for all to a healthy and normal life. In doing so, I want to shed light on the moral economy, upheld by the “gift of life” metaphor, in which what is considered to be a normal life is given certain meanings and in which the complex nature of transplantation is narrowed down to a problem of a shortage of organs (Kaufman, Russ, and Shim 2006; Siminoff and Chillag 1999).

THEORETICAL AND METHODOLOGICAL CONSIDERATIONS

In the “gift of life” rhetoric, transplantation is provided with a normalizing capacity. Framed in this manner, receiving a transplant not only restores “physical comfort,” but it also facilitates the resumption of “social duties” (Frank 1997, 80). Thus, health does not equal normality but is a crucial ingredient of it. Anthropologist Megan Crowley-Matoka has eloquently shown how, within the practice of kidney transplantation in Mexico, the concept of health is inextricably linked to societal norms on a wider level. Included here are “culturally potent and highly gendered images related to the family—specifically the ability to support a family (through employment) and to have a family (through marriage and reproduction)” (Crowley-Matoka 2005, 826). But the promise

of normality accompanying the “gift of life” metaphor could be described in more general terms. Following sociologist Nikolas Rose, I would like to argue that transplantation framed by the “gift of life” is akin to Rose’s characterization of the contemporary free individual. According to Rose, in today’s “‘advanced’ liberal democracies” “individuals [are] governed through their freedom” (1999, 84). At work here, however, is freedom in a particular sense, “understood in terms of the capacity of an autonomous individual to establish an identity through shaping a meaningful everyday life” (ibid.). Governed through freedom in this sense, the individual is forced to actively work on, be responsible for, and actualize him- or herself (ibid., 164–66). As sociologist Chris Shilling has shown, in late modernity this work is often carried out through an orientation toward the body as a project. In the present, Shilling argues, individuals are involved in “body projects” that serve to manage the perceived “unfinishedness” of the self by working on the body (2003, 4–7, 158). Normality as freedom thus becomes a question of an individual’s ability to take control over and turn the body and self into a personal project. Framed by the “gift of life,” a transplanted individual has this ability, while a person on dialysis does not. Consequently, what is concealed by the “gift of life” metaphor is, on the one hand, the fact that the transplant recipient is not cured and may experience illness symptoms, and, on the other hand, that, although ill and dependent on a machine, the dialysis patient does work on him- or herself and may experience a sense of freedom.

In this chapter I wish to unsettle this one-sided image of dialysis and transplantation by giving an account of the

complexity characterizing the relation between the two treatment alternatives. Since the fall of 2009 I have conducted ethnographical research at one dialysis unit in Riga and three in Stockholm. The material thus gathered consists of observations of the day-to-day care and interviews with patients, nurses, nephrologists, and transplantation surgeons.² The purpose of conducting the study within two national contexts is, on the one hand, to examine the contingency of medical practice by paying attention to its materialization within two different historical and sociocultural contexts and, on the other hand, to study late-modern biomedical practices as cultures of their own, containing values and norms and shaping and reshaping the lives and self-understandings of those who become part of them. In the context of this chapter, however, the focus will be on the latter, since my aim is to show how the globally occurring metaphor of the “gift of life” conceals the complexity that is inherent in dialysis and transplantation as such. In this chapter I analyze the narratives of dialysis patients who have experienced one or more transplantations and are now back on dialysis. Rather than portraying transplantation as a straightforward path to health, these persons’ stories make visible the complexity accompanying it. Here, the body plays an essential role.

In order to understand this complexity and the role of the body in it, I use philosopher Annemarie Mol’s concept of the body multiple (2002). According to Mol, medical practice enacts a multiplicity of bodies. Both diagnosing and treating a disease require the practicing of several practices, and even though each of these revolves around the same condition,

they all enact their own object—that is, their own disease and thus their own body, Mol argues. The use of the term enactment is a result of Mol’s conviction “that *ontologies* are brought into being, sustained, or allowed to wither away in common, day-to-day, sociomaterial practices” (ibid., 6, 32–33). Thus, the different practices that enact a disease result in a multiplicity of objects (ibid., 33, 46). However, as Mol writes, “a single patient tends to be supplied, if not with a single disease, then at least with a single treatment decision” (ibid., 84). But if there are multiple bodies, how is this achieved? Mol’s answer is coordination. In order to agree on a diagnosis and a therapeutic intervention, the different bodies have to be coordinated. This coordination is achieved by medical practitioners who add, calibrate, and translate the body multiple into one composite object (ibid., 71, 83–85).

Rather than focusing on the coordinating work done by medical practitioners, my intention in this chapter is to attend to the coordination work done by patients. Since my conviction is also a phenomenological one, I believe that there is an embodied person who encounters the body multiple of medical practice and both participates in its enactment and attempts to coordinate among its objects in order “to make sense and give meaning to his or her new situation” (Mol 2002, 15). Thus, my primary focus in this chapter is not on the care practice as such. Instead, I direct my attention toward how the body multiple emerges in the narratives of the interviewees. I argue that the body multiple is both enacted and coordinated in these stories, since they are simultaneously about and linked to the medical prac-

tice (cf. *ibid.*, 20). Thus, the questions I pose are concerned as much with how persons with kidney failure coordinate between their lived body and the body multiple as with how they coordinate between the bodies that make up the body multiple as such.

In the first two parts of the chapter the focus is on the interviewees' narratives of their experiences of transplantation. First, the erratic individual body that emerges when transplantation goes wrong is discussed, and then the complexities of the matching process, multiple retransplantations, and the quantifiable body are in focus. The third part of the chapter deals with the complex relation between the dialyzed and transplanted body, while in the fourth part, the personal body, enacted in dialysis practice, is in focus.

THE ERRATIC INDIVIDUAL BODY

When Veronica, who receives her treatment at one of the units in Stockholm, was transplanted it became painfully clear to her that she embodies not only a body with a specific diagnosis but also a body that reacts uniquely to therapeutic interventions. The kidney she received from her husband functioned for two years. But it never worked well enough for her to feel healthy. "I couldn't be happy," she says. "People could, for example, say to me, 'But Veronica, you're away from dialysis now,' implying that I should be happy about that. But when I didn't feel well, I couldn't..." The reason she did not regain her health following transplantation, she learned, was due to her disease "attacking" the transplanted kidney. The risk for such a scenario was known all along by the physicians, but "they tell me now because now they

know how I reacted," Veronica says. The treating doctors had hoped that they would be able, by means of special therapies, to stop the attacks by her disease. But unfortunately, they did not succeed. Instead she became worse and the treatments were discontinued. All in all, Veronica describes her experience of transplantation in negative terms. In contrast to the public image of transplantation, her life with a transplant was characterized by ill health and dependence on caregivers and family members.

Veronica's experience of transplantation is born out of a tension inherent in medicine, namely, that between the diagnosed body and the erratic individual body (cf. Mol 2008, 26–27). In the example above, these two bodies are both points of departure for and products of the procedure. The risks associated with transplanting a person with Veronica's diagnosis are known, but so, too, is the fact that not every body reacts similarly. However, the only way of resolving the tension between these two bodies is to go through with the procedure. By attempting transplantation one may study the reaction of the individual body and subsequently coordinate it with the risk estimation accompanying the diagnosis.

However, if the procedure fails, the consequences may be severe. In Veronica's case the physical and mental strain caused by transplantation was arduous. Interestingly, though, she seems capable of aligning her negative experiences with the information about the enhanced risk associated with her diagnosis and the need to test the reactions of her body. When, following her transplantation, it is recommended that she not opt for a second transplantation, she explains her decision to follow the recommendations by

reference to her difficult experiences. “I want to be more careful. I don’t want to risk getting worse,” she says.

Some might argue that the erratic individual body is a fundamental aspect of all human life. Since we are all biologically different we are always aware of the possibility of our bodies behaving in a unique and unpredictable way. Essentially, it is the uniqueness of my embodied appearance that assures a person that it is I he or she is addressing. But ordinarily this does not cause me to thematize my own body. It is not my body as an object that is addressed but I as an embodied subject. This is true for my own engagement with the surrounding world as well. It is as an embodied subject that I use things and meet people. Thus, the body is ordinarily “absent” from my attention (Leder 1990). But since it is made of flesh, skin, and bones, it can always be thematized as an object. According to philosopher Drew Leder, this thematization typically occurs when the body is experienced as “problematic and disharmonious” (1990, 70). Leder’s examples are disease and pain. He argues that, in disease and pain, a person is forced to direct his or her attention *to* rather than *from* the body (ibid., 83). Leder terms this state “dys-appearance.” In the state of dys-appearance the reason for the thematization of the body comes from within the body itself. However, a person may also be forced to attend to his or her body as a product of a societal situation. There may be power relations that orient a person toward his or her own body. Leder labels such occasions “social dys-appearance” (ibid., 96; see also Young 2005). Both social dys-appearance and dys-appearance always take place in societal situations and are therefore always interpreted and acted upon

within a sociocultural context. What distinguishes the two dys-states from each other is their origin. Dys-appearance originates from within the flesh and bones of the physical body, while social dys-appearance is caused by something external to this sheer physicality.

Leder's characterization of social dys-appearance always seems to presuppose the presence of the Other, the presence of a person or a group of persons who "refuses cotranscendence" and therefore forces me to thematize my body as something problematic (1990, 96). However, I would like to argue that the presence of a powerful system of knowledge, in my case biomedical knowledge, can have the same effect. As we shall see below, the practice of biomedical knowledge enacts a body multiple that forces persons with kidney failure to thematize their bodies in a number of ways.

In the context of this chapter I am interested in the constant intertwining of and interplay between dys-appearance and social dys-appearance present in the interviewees' stories. The occurrence of such interplay is pointed out by Leder, but only as a process that reinforces both types of dys-appearance (1990, 98). In my informants' stories it is apparent that the encounter between a dys-appearing and a social dys-appearing body may have an alleviating effect. Or rather, it may orient a person in a way that produces strategies for managing or avoiding the dys-state.

If we return to the erratic individual body, it becomes clear that it can emerge as both types of dys-appearance. When I fall ill, Leder writes, "I can no longer take the body for granted" (1990, 89). Thus, dys-appearance may cause an

awareness of the erratic nature of the body. But in the example above, Veronica also meets the erratic individual body as a product of the medical practice. She learns that her body has reacted in an unpredictable way to the treatments that the doctors had hoped would prevent her disease from attacking the transplant. Here, a specific version of the erratic individual body emerges, one that is a product of the social situation that she is in, an erratic individual body created by the failed attempt of medicine to restore her health. What in this case becomes erratic is that which at present falls outside the knowledge and mastery of medicine. Thus, the erraticism produced is an intrinsic feature of the particular biomedical practice that Veronica is enmeshed in. When a person is waiting for a transplant, the expected outcomes of the procedure—for example, improved health and quality of life—become incorporated into the lived reality of the person waiting.⁵ Therefore, the very experience of the erratic individual body is deeply intertwined with the context in which it occurs. But, as argued above, this erraticism is also a fundamental quality of the lived body as such. That medicine, in its ambition to produce diagnosed and treatable bodies, deals with unique physicalities is a fact emphasized by all interviewees, patients as well as medical personnel. Thus, the erratic body haunts medicine wherever it goes, but the way in which the erraticism emerges depends on the specific biomedical practice that enacts it.

Fortunately, Veronica is able to coordinate between the social dys-appearing body created by medicine and the dys-appearing body she experienced while living with her dysfunctional transplant. This not only orients her in a way

that gives meaning to her suffering, but it also allows her to avoid it by not opting for retransplantation.

Thus, the coordination of the dys-appearing and the social dys-appearing body orients her toward transplantation in a specific manner. From this perspective, transplantation, rather than being a routine and straightforward life-saving therapy, becomes a risky and difficult endeavor. This orientation toward transplantation is shared by a majority of those who have returned from transplanted life to dialysis. However, many do not, like Veronica, know why the transplanted kidney ceased to function or never started to work in their bodies. This orients some to stress the importance of accepting the unpredictable nature of transplantation and others to speculate about what might have gone wrong. Valda, who receives her treatment at the unit in Riga, connects the high level of the immunosuppressive drug Sandimmune detected in her blood at a routine checkup to the start of the rejection of her first transplant. She says:

Humans aren't equal. Every human being has a totally different organism. I think that one has to work on this issue more, because you cannot prescribe drugs based only on weight in kilos. Someone weighs more but absorbs drugs better. Another has worse absorption [and even though] he is slimmer ... needs more.

Here, the erratic individuality of the body is evoked again. Now in the form of a body that medicine does not pay enough attention to. Apparent in Valda's words are the expectations on medicine that accompany biotechnologies such as transplantation. The promise of the “gift of life” to return the

transplant recipient to a normal life relies on the promise of biomedicine as a whole to know and tame the body. Thus, Valda has the right to demand that more attention be paid to the problem of drug absorption.

TRANSPLANTATION AS A LOTTERY AND THE QUANTIFIABLE BODY

But transplantation involves more than one body. It relies on the merging of two. In a way this is precisely what the “gift of life” metaphor tells us: one person has to give a bodily gift in order for another person to survive. But in its one-sided focus on the insufficient number of people willing to donate, the “gift of life” metaphor conceals the complexity that is at work when two bodies are to be matched. Consequently, attention is also diverted away from the responsibilities taken, knowledge gathered, and work carried out by the dialysis patients who try to navigate through this complexity.

In contrast to the dominating supply-and-demand rhetoric, many of my informants’ stories are oriented toward the complexity of the matching process. With the experience of the return to dialysis and the loss of function of the transplant come insights into the uncertain and uncontrollable nature of the matching of the bodies involved. This even prompts some of my informants to refer to transplantation as a lottery.

Dmitry, who receives his treatment at the unit in Riga, is one of them. He has been transplanted on two occasions. The first transplantation gave him nine years of what he terms an “absolutely normal life.” The second, however, was unsuccessful. When we meet for the first time in October

2009 he tells me that he wishes to wait for a long time for the third transplantation. This has to do, first of all, with the complications he suffered in the wake of his second transplantation. During a period of eleven months he was hospitalized on numerous occasions. Dmitry describes this year as "lost" and says, "If the second kidney had worked for a longer time I would probably have another view of life." Now he has come to the conclusion that transplantation is a lottery and that it does not "depend so much on cross-matching but on physiology—to what extent people match each other." What Dmitry means by physiology here is unclear but it is evident that it is something that goes beyond the control of medicine.

However, Dmitry's wish to wait for a longer time is also motivated by the severity of the third transplantation. "The third transplantation is a very serious step," he says. "It is [a] longer [operation] than the first and second transplantation since the kidney is placed in the center [of the body], under the stomach [...]. You must be ideally healthy at that moment, and the idea needs to ripen in your head." Like many of his fellow patients, Dmitry is also aware of the fact that the survival rate of the transplanted kidney decreases with every attempt. He refers to a study conducted by Russian nephrologists that gives the third transplant a 25 percent chance of survival.

Added to these uncertainties are the challenges of coordination. These come to the attention of dialysis patients in different ways. They are, for instance, hinted at in the information presented to patients when they are admitted to the waiting list. When Valda's doctor told her about the pos-

sibility of being admitted to the waiting list he made sure to inform her that “it is not for bread or sausages or whatever, but [it depends on] a match.” By contrasting the waiting list for transplantation to the queues for food common during the end of the Soviet era, Valda’s doctor implies that there are more complicated factors than time involved. Consequently, a majority of my informants have only received vague information about the expected waiting time. But the challenges of coordination also come to some patients’ attention through the experience of being called in for transplantation without being transplanted. This may happen for a number of reasons. On some occasions, the crossmatching proves to be poor. On others, an infection makes transplantation impossible. When Sven, who is treated at one of the units in Stockholm, received a phone call one night from the transplantation department, he was informed from the outset that he was not the primary candidate for the kidney. So, when the transplantation did not happen, he was not surprised.

How the complexity of organ coordination has come to Dmitry’s attention is unclear. But when we meet for a second interview and I express my wish to know more about why he considers transplantation to be a lottery, he gives a detailed account of what transpires when organs from a brain-dead donor become available. The protagonist of his story is the coordinator.

She calls one person and he has a temperature. Then she calls another one and he has a cough. Then she calls a third person and he’s ill. They all fall away. And that’s the way the choice is made, independent of whether you are fourth

or fifth or tenth on her list. [Probably] the kidney would match [...] the first person on the list [best], for him it could probably function for ten years. But it matched me, so they put this kidney in me.

As we have seen, there are a number of complex issues motivating Dmitry's wish to postpone the third transplantation. Of great importance is, first of all, his experience of the two previous transplantations. It is the shifting outcome of these that has oriented him toward the randomness of the procedure. Here, the erratic individual body emerges again. But unlike Valda, Dmitry does not expect medicine to be capable of taming it. Instead, he argues, it is up to him to be physically and mentally prepared for the procedure. Much like Rose's and Shilling's characterization of the contemporary free individual, Dmitry is forced to turn inward and actively monitor and work on his mind and body in order to navigate through the complexities of transplantation. In this process he becomes required to assume personal responsibility for the timing of his admittance to the waiting list for transplantation.

But the chance of drawing the winning ticket in the transplantation lottery is not completely random. In addition to the erratic body there is a quantifiable one. This body is evoked when Dmitry refers to the survival rate of the third transplantation. Most of my informants do not, like Dmitry, report the findings of scientific articles, but they are all aware of the increased risk associated with each retransplantation. Thus, becoming directed toward the quantifiable body is inevitable when one decides how to live and what

to do following the return to dialysis. In Dmitry's case, the 25 percent survival rate of the third transplant reinforces his orientation toward a longer waiting time.

According to Fredrik Svenaeus, the ability to measure and quantify the body, developed during the nineteenth century, was essential to the emergence of modern medicine. Through advances made in scientific disciplines such as physics and statistics it became possible to make diagnoses and prognoses by studying and systemizing the numerical outcomes of tests facilitated by new medical technologies (Svenaeus 2000, 32–33). The quantifiable body is thus an intrinsic part of modern medicine. However, as with the erratic individual body, the way in which it emerges varies with each medical practice. Thus, the quantifiable body in the form of a 25 percent survival rate for the third transplant orients Dmitry toward the procedure in a specific manner.

But in the example above it also becomes clear that those who return from transplanted life to dialysis encounter not only a body multiple but also a transplantation multiple.⁴ From the perspective of dialysis, the lifesaving potential of transplantation is not stable. It decreases with every attempt. Consequently, the first, second, third, and fourth transplantation are all different from each other and orient the embodied person toward the body multiple of dialysis and transplantation in different ways.

Thus, when the multiplicity and complexity of transplantation is taken into account, characterizing life with dialysis as mere waiting, suffering, and dying becomes impossible. Instead, the responsibilities taken and the work done by persons on dialysis appear. So, too, does the interplay between

the two types of dys-appearance. Dmitry's experience of living with a dys-appearing body following his second transplantation, combined with the social dys-appearing body materialized in the form of the quantifiable body, orients him toward a longer waiting time.

THE RELATION BETWEEN THE DIALYZED
AND THE TRANSPLANTED BODY

In the following I turn my attention toward the relation between the two treatment practices that I study. In these practices two bodies are enacted: the dialyzed body and the transplanted body. As I have argued above, in the public image the dialyzed and the transplanted body are imagined as each other's opposites. While the former is healthy, free, and active, the latter is seen as characterized by ill health, dependence, and passivity. Although one-sided, this image does exist in my material. Those who have experienced life with a fully functioning transplant not infrequently describe it with words similar to those above. When Yevgeniy, who receives his treatment at the unit in Riga, was transplanted for the first time the kidney functioned for three years and nine months, a period he describes as follows: "I felt like a healthy person. I used drugs, of course. I worked. I felt very good. Practically speaking, I was a healthy person." This may be contrasted to how Filipis, who is also treated at the unit in Riga, characterizes the role of dialysis in his life. "Dialysis is the most important activity, and only after that [come] all other things. Dialysis [has] reorganized my life." To describe dialysis as an intrusion into life is common among my informants. It is not only time consuming; a

majority also experience side effects such as blood pressure drops, nausea, and fatigue (Idvall 2007b, 153–54; Russ, Shim, and Kaufman 2005; Berglund and Lundin this volume).

None of my informants, however, view transplantation as a definite solution to these problems. Instead, as we have seen, it emerges as a multiple and variable treatment alternative that, on the one hand, has the potential of providing an improved quality of life, but, on the other, might fail and cause even greater suffering. Thus it follows that a life with dialysis always has to be taken into account. But the “here” from which this taking into account takes place is never stable, and neither are the different bodies and multiple forms of treatment that are encountered. Consequently, in my informants’ stories the relation between the dialyzed and transplanted body goes beyond simple opposites such as health and illness, normal and abnormal, freedom and dependence, and so on.

“It is like intermittent care,” Marianne says. “Sometimes you are treated with dialysis [and] sometimes you are treated with a transplant.” Marianne has decided, however, not to opt for a third transplantation. Her previous two have been filled with repeated infections and courses of antibiotics. Now she manages dialysis by herself at her home in Stockholm. She has furnished one room of her apartment with a hemodialysis machine, a bed, a telephone, and a TV set. Here she spends three to four hours, four to five evenings a week. Marianne follows her own prescription, which means that she decides how many hours she will spend on dialysis each week. “And this gives me a sense of freedom with the machine, I think, with my life ...” she says.

When Marianne explains why she is not opting for a third transplantation, it is in a rather pragmatic way.

It is good of course to rest your vessels. They get really exposed on dialysis. So that's of course an argument for [transplantation]. Another argument for [transplantation] is to escape the constraint. [...] So there are a lot of advantages if you count like that. And then there are the disadvantages. And then you have to consider them, and that's what I have done.

What motivates Marianne not to go through with a third transplantation is, besides the many infections she suffered following her two previous transplantations, the major surgeries she would have to undergo. A third transplantation, she says, would entail not just inserting a new kidney into her body but also taking one of her old transplants out. Added to these disadvantages are the immunosuppressive medications and their side effects.

The pragmatic way of reasoning found in the quote above is evident in many of my informants' stories. Even though a majority of those who have the possibility choose to opt for another transplantation, it is not, as I have shown, without taking into account the uncertainties involved. These considerations are often far away from the “gift of life” rhetoric. Marianne's orientation toward the state of her vessels shows that she does not consider transplantation to be capable of solving her problems once and for all. When she highlights the importance of *resting* her vessels, she takes for granted the temporal limit to the functioning of the transplant and a return to dialysis. Thus, Marianne is not primarily ori-

ented toward transplantation as a lifesaving technology, but rather as a rational way of resting her body from the strains of dialysis. However, she also brings up the independence of the transplanted body. But it is clear that the side effects of her previous two transplantations and the major operations she will have to go through weigh more heavily. Posed against the freedom of the transplanted body, furthermore, is the freedom of the dialyzed body. Following her own prescription makes a feeling of freedom possible.

By working on herself in the form of self-care dialysis, Marianne is able to give life with dialysis a meaning that comes close to normality in the form of freedom. She reaches her decision not to opt for a third transplantation by weighing the pros and cons of her life with dialysis against those of her life as transplanted. In the “gift of life” rhetoric, attention is diverted away from the need for such pragmatic considerations, and also from the potentiality of a feeling of freedom when living with dialysis.

Another way in which the complexity of the relation between the transplanted and the dialyzed body emerges in my informants’ stories is through their orientation toward the toxic body. The toxic body is an illustrative example of the contingency of the body multiple and the coordination it demands of the person encountering it.

The main aim of dialysis is to rid the patient’s blood of its toxins. The level of toxins in the blood is regularly measured in order to evaluate the efficiency of the treatment. Thus, dialysis patients become continually oriented toward the problem of the toxic body. For some, this orientation becomes problematic when, following transplantation, they

have to take a large amount of immunosuppressive medication. After the loss of function of his transplant, Sven met some of his previous fellow patients who had decided "that they wouldn't go near these kidneys and these toxic pills." Although Sven had not experienced any side effects during the time he was transplanted, he had contemplated the possible consequences of the medication. And when his fellow patients expressed their view, he started seriously considering whether or not he would opt for a second transplantation. Now, when this thought process has been going on for a while, Sven has decided that he will probably say no if he is offered admittance to the waiting list again.

Carlos, who has just moved to the self-care unit in Stockholm, also labels the immunosuppressive medication toxic. This has not, however, prompted him to opt against retransplantation. In his story, the toxic medication functions instead as a means of describing the hardships of life with a transplant. Carlos's transplanted kidney functioned for thirteen years. During this period he "traveled a lot" and "did a lot of things." So "of course you feel a lot better, you have freedom, but you're not 100 percent," he says. He thinks the reason he did not feel 100 percent was the immunosuppressive medications. They upset his stomach, made him tired and depressed, and caused a period of panic attacks. Now, when he is back on dialysis, his stomach and his head feel better, he says.

Thus, the toxic body is not only one; it is multiple. It is enacted in dialysis as well as in transplantation but is afforded totally different meanings in the two practices. For a person who has experienced both dialysis and transplantation, the

two versions of the toxic body may become “incompatible”; they may be experienced as an embodied contradiction (Mol 2002, 35). With dialysis, ridding the body of its toxins saves the patient’s life. With transplantation, the same end is achieved by the intake of toxic medication. Thus, coordination is required. One way of coordinating incompatible bodies is, according to Mol, to produce a hierarchy, where “one of them is made to win” (ibid., 84). This is what Sven does when he makes the dialyzed body the winner and Carlos when he makes the transplanted body the winner.

THE PERSONAL BODY

In the following I wish to nuance the image of life with dialysis as mere waiting, suffering, and dying by turning my attention toward a body that emerges in the hemodialysis practice, namely, the personal body. This body is personal rather than individual since, to a varying extent, it becomes known, acted upon, and controlled by the person who embodies it. Through being oriented toward the personal body, a person gains knowledge about his or her embodied reactions and relations to the illness and treatments. But the reverse is also true: for the personal body to emerge, a person has to be oriented toward his or her own body with the intention to know it and to work on it.

In being oriented toward the personal body, the aim is to make personal all manifestations of the body multiple. By continually attending to the diagnosed, erratic, quantifiable, dialyzed, transplanted, and toxic body, a person gets to know and becomes able to control and alter his or her body. This idea rests firmly on a view of the body multiple

as always being about the body of the patient, but also on a view that as an embodied being one always already has a unique knowledge of one's own body. Therefore, it is only natural that a patient takes responsibility for and engages with his or her body.

This relation of the individual to his or her own body is akin to Rose's characterization of the advanced liberal individual and to Shilling's "body projects." But an interesting parallel can also be drawn to the changing role of the patient that has been taking place during the last few decades. This new patient is active in relation to his or her care, takes responsibility for it, and has knowledge about both diagnosis and treatment alternatives. He or she participates in the decision making and has the opportunity to choose among health care providers and treatment alternatives. In relation to the medical practitioners this patient is often referred to as autonomous and empowered. He or she is considered to be a unique individual with special needs and wishes (Hansson 2006; Idvall and Lundin 2009).⁵ The new patient is thus an individual who is oriented toward a personal body.

Johan, a Swedish nephrologist working at one of the units where the medical personnel manage the treatment, finds dialysis patients' involvement in and awareness of their own bodily state to be the most interesting aspect of nephrology. "Since they are very aware of themselves, their disease, it becomes easier to manage their treatment ...", he says. This, in turn, means that he gets more positive feedback. "When they feel the results they become very happy and [...] that is then returned to you." According to Johan, it is the constant flow of information between medical personnel and patients

that is the primary reason for the awareness among patients of their bodily state. He continues: “The character of this disease requires frequent checkups, and frequent checkups means frequent test taking, and, once again, discussions about this. So there are constant repetitions, and that way they learn a lot.”

But becoming knowledgeable about the body is not enough. Dialysis patients also have to carefully monitor and act upon it. This is particularly evident when it comes to the restrictions in fluid intake to which all dialysis patients are subjected. Valda’s story illustrates this.

Can you imagine that I am not allowed to drink a cup of water during the whole day? Because in everything I eat, in bread and in other [foodstuff], there is water, and it accumulates in my body. And then it [results] in how much weight I have to drop every time [dialysis session], since the fluid is not discharged by [my body]. I think about it all the time.

Before every dialysis session all patients weigh themselves. This is done in order to determine the amount of fluid that needs to be removed from the body during the treatment. “Taking off” a lot of fluid is, for many, very demanding and may result in feelings of fatigue and nausea that often linger for hours. Moreover, only a limited amount of water can be removed during a dialysis session. If, over an extended period of time, a person does not sufficiently reduce his or her fluid intake, water will accumulate and eventually find its way to the lungs. It is therefore not strange that Valda constantly monitors the amount of fluid that goes into her body.

understood early on that her body had a hard time "carrying" a lot of fluid. "I see other patients who can carry a lot more fluid and [...] it seems like they can cope a lot better. I can't stand a lot. I get easily nauseous, very easily nauseous." Thus, there is no universal formula or method to manage the fluid intake. In order to monitor and control the reactions of your body you need to get to know it in all its uniqueness. But as I pointed out above, the reverse is also true. Getting to know the uniqueness of your own body requires an orientation toward it.

This is also evident when it comes to the frequent tests and checkups—referred to above by Johan—that dialysis patients undergo. These, too, cause patients to become not only knowledgeable about but also active in relation to their bodies. Rune, who receives his treatment at one of the units in Stockholm, greatly values the information that the monthly tests give him. "I want to be informed about... well, about my condition, [...] what I don't feel but which the tests reveal ...", he says. Comparing the latest test results with those from previous months allows him, furthermore, to discover tendencies of improvement and exacerbation. "I am in no way an expert," he continues, "but I want to know about what concerns me [...] and what I can do to improve it." Thus, the frequent tests and checkups not only inform a dialysis patient about his or her bodily state but also orient him or her to seeing tendencies in and working on the body. Here, the presence of the body as a personal project becomes strikingly clear. Not all dialysis patients pay as much attention as Rune to the results of their tests, but my empirical data indicate that the sheer amount and frequency of medical

checkups and tests always, to some extent, result in an orientation toward the personal body.⁶

Thus, rather than being characterized by mere waiting, suffering, and dying, the hemodialysis practice revolves around how life with the treatment may be improved. Permeating the four units I have visited is the idea that things can and should be done about the state of the body, and that the more the patient gets involved the better the results. However, my material also contains many descriptions of life with dialysis that are seemingly akin to that conveyed by the “gift of life” metaphor. A majority of the dialysis patients I have met describe themselves as being at the whim of the symptoms of the disease and the regime of the treatment. The end-stage state of the kidney disease and life with dialysis are often portrayed as being beyond individual control and something that simply has to be accepted (cf. Idvall 2007b, 153–54; Russ, Shim, and Kaufman 2005, 305). Thus, there are limits to the extent to which the body can be personalized. Furthermore, the prerequisites for turning the body into a personal project are framed by the treatment practice as such. It is first and foremost from medicine that dialysis patients find the tools required for personalizing their ill bodies. But rather than being mutually exclusive, the imperatives to accept the malfunctioning body and to act to personalize it coexist. This clearly illustrates the complex situation in which dialysis patients find themselves.

There is, however, one group of patients who describe themselves as being more able to transcend the limits that kidney failure and regular dialysis create. These are the self-care patients.⁷ “I can’t adapt myself to dialysis, it can’t

be done," Carlos says. "I know where my limits are. [...] I know that it's hard to 'take off' a lot of fluid from me. I know that I feel bad after three hours [...]. So I need to adapt dialysis to me." Carlos tries to line up the conditions that need to be met in order for him to endure a life with dialysis. Apparent in the quote is the personal body. Carlos repeatedly uses the words "I know" to emphasize the knowledge he has about his own body. This knowledge tells him that regular dialysis does not suit him. He needs to dialyze more than four times a week; otherwise the treatment is too hard on him. However, the only way for him to achieve this end is to begin self-care. At the time of the interview Carlos has recently moved to the self-care unit and started treating himself. "It's me and the machine [now], no one else, only if I need help. But I'm in charge," he says. Self-care gives him "the freedom to choose" the length and frequency of his dialysis sessions. Consequently, he can adapt the treatment to himself and "live a good life with dialysis."

As touched on above, Marianne describes her life with dialysis in similar terms. Having the treatment at home gives her a sense of independence and freedom. "It's incredibly valuable to be in control of your life more, which is the case when you have it at home," she says. Moreover, home-hemodialysis enables her to plan her week more freely. The week of our interview, for instance, she will only take her treatment on four occasions since she has her son's birthday party and a ballet to go to. But this is a minimum. She needs to reach at least fifteen hours a week to feel reasonably well.

Both Carlos and Marianne have come to gain a lot of knowledge about their bodies. But more than that, they have

been afforded the tools to turn their knowledge into action, to engage in their own “body projects.” Self-care dialysis has made it possible for them to know and work on themselves and their bodies in a way that facilitates a self-presentation containing many of the key words used to define the new patient and the advanced liberal individual. Although they both tell about the uncompromising intrusion of dialysis into their lives, Carlos and Marianne are still able to describe themselves as relatively free, in control, able to choose, and independent. Their orientation toward themselves through self-care dialysis aligns them with the contemporary characteristics given to a qualitative and normal life. Unfortunately, however, such alignment is rendered invisible by the “gift of life” metaphor.

But how, then, can being oriented toward one’s own body as a personal project be viewed as normal when, as Leder points out, our bodies are ordinarily absent from our attention? In fact, Leder’s main argument is that the disappearance of the body is an essential precondition for our engagement with the surrounding world (1990, 90). It is by being directed *from*, not *toward*, our bodies that we are able use the objects and interact with the persons around us. Thus, dys-appearance and social dys-appearance not only orient us toward our bodies but also shut us off from our engagement with the world. But Leder is careful to point out that dys-appearance and social dys-appearance are not the only modes by which we attend to our bodies: “There are a limitless variety of situations in which we experience or take action upon our body in the interest of enjoyment, self-monitoring, cultivating sensitivity, satisfying curiosity, or for no

particular reason at all” (ibid., 91). What distinguishes dys-appearance from other forms of bodily attention, however, is that it exerts a non-negotiable “demand” on the individual: “Other sorts of bodily thematizations have a certain optional nature” (ibid.). This is not to underestimate the compelling nature of the contemporary sociocultural imperative to be oriented toward the body as a personal project; Shilling would almost certainly agree that body projects not infrequently cause the body to dys-appear. But, for dialysis patients, after a while the distressing bodily symptoms and the asymmetrical encounters with the medical gaze of doctors and nurses become part of the habit of everyday life. Nurses and doctors become almost like colleagues or even friends, and test results are used as instructions on how to engage better with the surrounding world—what to eat and drink, how much to exercise, and so on. Furthermore, in the self-care patients’ stories, the optional nature of their orientation toward their bodies is central. It is the possibility of adapting the treatment to bodily needs and personal intentions that they value most. But, as I have shown in this chapter, this does not mean that they never experience a dys-appearing body. Nor does it mean that being oriented toward the body as a personal project automatically causes it to dys-appear. Instead, being engaged in a body project may facilitate an engagement with the world since it enables an anticipation and prevention of dys-appearance and an alignment with the contemporary ideals of responsibility, activity, and independence. Important to keep in mind, however, is that the person who attends to the body is always embodied. “Gazing upon the body-object is a body-subject, though the physical-

ity of the latter may remain tacit,” Leder writes (1990, 88). Thus, when orienting oneself toward one’s own body, the body is always both present and absent.

What I have wanted to show with this short excursion into the theories of Leder and Shilling is that there are different modes of orienting oneself toward the body. The consequences of these different modes are complex and varying and have to be analyzed as part of the societal situation in which they occur. This is what I have attempted to do here.

CONCLUSION

In this chapter I have unsettled the conception of life with dialysis as mere waiting, suffering, and dying, and life with a functioning transplant as a return once and for all to a healthy and normal life, by unmasking the complexity characterizing the relation between the two treatment alternatives. This complexity has emerged in my interviews with persons who are back on dialysis after transplantation. I have argued that these persons’ encounters with the body multiple of dialysis and transplantation care result in a variety of orientations toward the two treatment alternatives. My analysis has shown that the simple opposition, sustained by the “gift of life” metaphor, between the waiting, suffering, and dying dialysis patient and the once-and-for-all saved transplant recipient does not hold. Among the dialysis patients I have met there is instead a widespread awareness of the limited durability of a transplanted organ and the many uncertainties accompanying the procedure. But rather than causing passivity, these uncertainties require active consideration. My informants’ encounters with the body multiple

of dialysis and transplantation care require them to actively and responsibly consider the two treatment alternatives from the “here” where they currently find themselves. In doing so, they not only have to gather knowledge about the biomedical conditions at hand but also turn their gaze inward and do work on their body and self.

But what, then, is the reason for the popularity of the “gift of life”? What kind of moral economy supports the use of this metaphor? And what purposes does the concealment of the complexities of transplantation and dialysis serve? Besides being the prevailing metaphor for promoting the donation of organs, labeling donation a “gift of life” serves two purposes. First, it safeguards the normalizing ability of biomedical intervention. Viewed from the perspective of the “gift of life,” transplantation not only saves the recipient’s life but also restores health in such a way that the life that was interrupted by the onset of illness may be resumed. The metaphor of the “gift of life” thus allows medicine to continue telling what sociologist Arthur W. Frank has called a “restitution narrative” (see Frank 1995, chap. 4). Second, transplantation imagined in this way sustains the moral economy in which an individual becomes responsible for working on and actualizing him- or herself. Freed from the passivity and suffering caused by the dialysis machine, the kidney recipient is able to resume responsibility for and take control over his or her body and self. Through the “gift of life” metaphor, a sharp line between normal–life with a transplant–and abnormal–life with dialysis–is maintained. Therefore, an acknowledgement of the complexities and risks associated with transplantation and the work done and freedom felt by

dialysis patients would blur this line. Thus, the metaphor of the “gift of life” not only promotes the donation of organs but also serves to keep distant the ambivalence that is so often a product of modern biomedical therapeutic endeavors.