

ANTONINA OSTROWSKA  
Polish Academy of Sciences

## The Struggle with Time in Chronic Illness

*Abstract:* It is worth looking at chronic illness with its pain, suffering and increasing limitations from the perspective of time. By time we mean subjective time relating to the perception and dynamics of the malady in the patient's impressions and the role which time plays in the structuring of the patient's life and experience. The main focus of this article is the experience of progressive kidney failure (uraemia), a condition which requires regular dialysis or kidney transplantation. Due to its specific crises, hopes and periods of waiting, painstaking medical procedures lasting many hours and turning points in the disease's trajectory, time and its passage are a particularly adequate instrument with which to analyse the experiences of patients with uraemia. These experiences are discussed against the backdrop of selected elements of health care and attitudes towards transplantation which provide the social context for patients' struggle with illness.

*Keywords:* time, chronic disease, trajectory, dialysis, transplantation.

### Distress, Illness, Time

This article was inspired by Jan Szczepański's (1988a) deliberations on the role of suffering, illness, senility and the passage of time in the lives of every man and woman. Writing about all these "human matters" he observed that human life can really be reduced to the battle with time. Jan Szczepański reflected on these matters during his long hospitalisation. His own experiences and perhaps sufferings made him ponder over the multiple types of time which patients experience—biological time, the subjective time of hope, the time of waiting.

What affects subjective time most [...] is distress which acquaints one with the hateful length of every minute, especially when it is measured with excruciating pain. Illness and suffering show us how time can destroy us and our bodies [...] Only the time of suffering provides a sense of passage of time and destruction, the anticipation of death, and it is also often the time of fear, he wrote (Szczepański 1988b).

My own thoughts concerning patients' experience of time (although free of personal accents) will refer to subjective time and will be based on observations and interviews with patients at a large hospital in Warsaw. They will reflect on their quality of life, the specific nature of the structure of time in illness, and above all time as it is experienced during people's routine activities but also time as it relates to people's biographic experience. For time, as Herbert Mead (1932) reflected,

...is the interpretative horizon for everything that happens to us. What is happening now is the consequence of what happened in the past and will have its aftermaths in the future. Memory, history, anticipation, plans for the future—elements of our everyday life and awareness are elements rooted in the structure of time.

Therefore, we view time as a social construct which we will use as a category for the analysis of life with illness, one which organises the patient's feelings and experiences which are so difficult to grasp and organise. When we say illness we mean chronic illness: illness which is long-lasting, difficult to treat, which has a significant impact on the quality of human life and, due to the limitations it incurs, challenges a person's freedom.

One of the first sociologists of medicine to draw attention to the role of time in the experience of illness and disability, treatment and rehabilitation, was Julius Roth (1963). In his analysis of the process of clinical rehabilitation, he juxtaposed the model of activity of medical teams who focus on quick and effective intervention and the model of hospital life and patient functioning which he called "slowed-down life." Roth showed how these two models clash and how they make it difficult to reach mutual understanding (Roth & Eddy 1967). It is worth mentioning that this was one of the first American studies of time conducted in the sociological convention. According to Elżbieta Tarkowska (1987), institutionalisation (hospitalisation, incarceration) or the experience of historical events which interrupt daily routines (wars, revolutions) were sociological facts which inspired the development of sociological analyses of time.

Social researchers who study the behaviour of the ill and disabled often tried to organise patients' behaviour and experience by seeking their sequential nature, some form of logic in their temporal dynamics. One of the most well-known examples is E. Kübler-Ross's theory. Kübler-Ross (1969) distinguished five consecutive stages or mental states experienced by patients in the terminal stage of cancer who are aware of their condition: denial, anger, bargaining, depression, and acceptance. The role of time as an intervening variable in the experiencing of progressively deteriorating illness is also present in Kathy Charmaz's (1991) qualitative study where she demonstrates the increasing effect of disease on quality of life and the patient's sense of self. The processes experienced during illness are reduced to three dimensions: chronic illness as an interruption, intrusion and immersion.

The dynamics of illness, its duration and the dying process can also be analysed in terms of the classic concept of the "dying trajectory" (Glaser & Strauss 1968). This concept reflects the consecutive changes in the state of the patient and her environment in the different stages of illness and treatment depending on the prognosis and the risk of death. Like the trajectory of the missile we can distinguish several segments of the journey, several stages of illness and accompanying experiences as they move through time and social space. This approach, developed later by Riemann and Schutze (1992), became an important theoretical conception and was used to analyse "suffering and chaotic social processes," not only relative to dying. The authors reflected that trajectories need not refer to terminal illness alone. Trajectories may be renewed in any pathological process or any distress and the end of one trajectory may mark the beginning of another one. Trajectories can also be interrupted and then reactivated. All trajectories have something in common, however and—the authors point out—characterise the suffering of the psychiatric patient, the life course of the alcoholic or the cancer patient as well as the student who experiences regular and degrading academic failure. It is worth picking out some of these elements such as:

being overwhelmed with events over which the individual has no control, at least initially, the feeling that these events are determined by uncontrollable extrinsic factors, disorganisation of daily routines, deteriorated ability to initiate and organise social relations and giving in to the mood and logic of distress as the dominant state of mind.

One of the better known works in the field of sociology of medicine linking social time with illness is Eviator Zerubawel's empirical study, *Patterns of Time in Hospital Life* (Zerubawel 1979). This book shows how time co-ordinates the operation and functioning of such a complicated social organisation as the hospital. It focuses on the rhythmic and repetitive structure of activities in the life of the organisation, the effort to maintain fluidity of action and synchronisation of different activities, i.e., on time as an organiser of the specific social order which accompanies illness. Meanwhile, the temporal structure of the patient's own impressions and experiences has been discussed by Wolfram Fisher (1982) in his book *Time and Chronic Illness*. This book encouraged me to take a closer look at the individual and social context of the struggle with serious disease in Poland.

In this article I would like to concentrate on the experiences of the patient and on the temporal perspective as an analytic category for this experience. Therefore I shall apply the concept of illness trajectory to the dynamic of illness and to the accompanying experiences as it is experienced by the patient. Trajectory, as we shall see presently, is neither continuous nor homogeneous, so the patient's experiences tend to be constituted by many coexisting trajectories rather than by one trajectory which organises the patient's life. Riemann and Schutze's proposals come nearest to my approach.

### **Time in Chronic Illness**

Chronic illness, by definition, contains the reference to time (time = *chronos*). As opposed to acute illness, with its sudden dynamic, chronic illness is long-lasting and becomes a permanent element of the patient's daily existence. And even if it does not lead to death directly, it is usually present until the end of life and systematically alters that life. It causes prolonged discomfort and distress, leads to social isolation and alters identity. It also modifies the patient's attitude toward his or her own body: with the passage of time, a clear opposition often develops in the patient's experience, i.e., me and my body (Fischer 1982). It gradually becomes not only a burden but also an obstacle; it is unable to do what the patient expect it to do, disappoints her and causes pain. Time and life with illness are also related in another way: continual confrontation with biographical experience, i.e. return to the past—a past without illness, a life without restricting disability and a violated self-concept.

The famous Polish psychiatrist, Antoni Kępiński (1978) also drew attention to the role of time in the analysis of the ill person's reality.

One of the first questions a person asks is *why?* and *what for?* From the early years of life until death these questions express the natural human need to impose some order on external and internal phenomena. The question *why?* strives to impose order on the past segment of the temporal axis whereas the question

*what for?* strives to impose order on the future segment (...) in the causal (past) and goal-directed (future) sequence.

As I said before, socio-temporal analyses often take sequence, i.e., the consecutive appearance of events in time, into account. When we analyse living with chronic disease, we can also distinguish several different phases. These phases are general enough to apply to various illnesses and to reflect the patient's various mental states and situational contexts. Roughly speaking, the illness trajectory has three stages ("trajectory segments"). The first stage of the experience of chronic illness is defined by the time needed to make a diagnosis and the procedures involved, i.e., the time which elapses between the first observable symptoms and the final diagnosis. This stage involves anticipatory anxiety. Worry mingles with anticipation of future restrictions, the need to make sacrifices and introduce modifications into one's life; however, there is still hope that the condition is a transitional one and that things will soon get back to normal. The patient begins to anticipate further progression of the illness, however, and to ruminate on the present state which may persist or exacerbate in yet unclear ways.

In the second stage of adjustment to illness the patient must learn to cope with existing limitations. To do so, she must interpret surrounding reality anew, attribute meaning to her illness and rediscover her personal identity. She is increasingly aware that the illness will not pass quickly. She must therefore develop effective ways of realising her tasks in changed conditions, develop a new priority hierarchy, and adapt to the regime of living with illness (Bury & Anderson 1988, Charmaz 1991). Every illness with its particular regime imposes certain temporal constraints on the patient's everyday life and alters the previous rhythm. The patient must take her medicine, measure her blood pressure or temperature regularly and will perhaps have to observe a special diet, change meal times and rest more. She will also have to go for regular check-ups and various medical treatments. Some of these treatments will collide with her daily agenda, others will require regular consultations with her doctor, the surgery or the hospital ward and, to comply with doctors orders, she will have to plan and restructure her time. Illness is a source of distress not only because of its symptoms but also because it deeply interferes with the daily routine. Fisher (1982) observes, that whether or not the patient is aware of it, her life becomes increasingly structured by time and waiting.

Adjustment to a life with illness will be susceptible to interferences and further modifications, however, thus determining the next stages of experience of illness and changes in adjustment patterns. These interferences will largely be caused by the development of new symptoms. It is very probable that, irrespective of periodical "crises" (aggravations and remissions), as time passes and the patient gets older, his general health and stamina will deteriorate. Every limitation of vital functions, deterioration of well-being, symptomatic distress and the need to alleviate it, and time-consuming therapy will affect the patient's relations with other people, restrict contact and often deepen social isolation. Loss of control of one's body becomes a source of anxiety—problems with incontinence or sudden vomiting embarrass the patient and her environment. Hence, with the passage of time, the patient will become more and more introverted and will focus more and more on her illness.

Life with illness can be very long-drawn-out in time, in some cases until the patient enters the third, terminal phase. This means a practically irreversible progression which cannot be stopped. In this phase the main purpose of medical intervention is palliative and the patient—if aware of his condition—experiences a stressful struggle with time or awaits death.

### **Empirical Exemplification: Dialyses, Transplantations, Time**

The foregoing and very briefly outlined stages are typical for many illnesses. However, a more thorough analysis of patients' experience suggests that different trajectories may be operating, not always smoothly, and that the three segments we have distinguished rarely do justice to the diversity of this experience. The very dynamics of the malady, its crises, remissions, available treatments or alleviating therapies, determine the different courses of individual trajectories and the frequent asynchrony of events. With time, the patient may also redefine her own situation, reorganise her experiences and increasingly identify with the sick role. Different patients' various psychological, social and situational contexts are additional modifying factors. Hence, what we need to do is distinguish several parallel trajectories, referring to different aspects of patient experience and to acknowledge that several trajectories may emerge in that experience, one by one.

In order to be less general, let us now discuss the specific nature of one particular disease and use it to illustrate its trajectories. The disease we have chosen is final renal failure. This condition is particularly adequate for our analysis because of its specific crises, hopes and expectations, pivotal moments and "temporal paradoxes." These elements are largely related to the progress of medical technology with respect to the implementation and proliferation of new therapies (haemodialysis, transplantation). On the one hand, these advancements generate enormous expectations but on the other hand they can also cause painful disappointment and mental breakdown if the great hopes attached to them cannot be fulfilled. The problems facing the health care system and the current availability of health care in Poland are the source of many stressful experiences.<sup>1</sup> Difficulty doing basic tests and obtaining specialist consultation, the prolonged diagnostic phase, poor access to dialysis all hinder the treatment process and cause much anxiety. Also, the prolonged wait for an adequate organ donor, is a source of frustration for many patients. In such cases the time of illness becomes a time of observation of aggravating symptoms and waiting for radical improvement which is theoretically possible but may never be practically available.

The choice of this particular disease is also dictated by social education reasons. In Poland transplantation has lately become a topic of public discourse. Accusations of corruption which the Ministry of Justice flung at the transplantologist community, though unconfirmed, captured the media's attention for many weeks. Potential donors

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<sup>1</sup> In a comparative study of European health care systems, access to specialist health care in Poland was particularly censured (Health Consumer Powerhouse 2007). The territorial deployment of specialist facilities is also a problem, resulting in access inequalities in different parts of this country.

became very suspicious of transplantation procedures. Soon after the alleged “corruptive practices” were publicised, the institution responsible for supervising transplantations (Poltransplant) noted a dramatic decrease in the number of secured organs. Within a month of the “corruptive events,” the number of organs for transplantation dropped more than three times (Pado 2007). Patients awaiting life-saving transplantation became the vicarious victims of the authorities’ spectacular anti-corruptive measures.

Much time will have to elapse before families regain their trust in potential donors (most often fatal accident victims). Not only must they be convinced that corruptive practices (if there were corruptive practices) were isolated facts. It is also necessary to spread the truth that organ transplantation is a real gift of life which may not only prolong life but also improve its quality in a significant way. All in all, irrespective of the recent controversies concerning alleged corruptive practices, Polish society’s willingness to donate organs to those who need them is declaratively high but these declarations have no practical confirmation. The main excuse for this reluctance is of religious nature. Another frequent excuse is the desire to maintain bodily integrity after death (CBOS 2007). This is so despite the fact that one of the Poles’ greatest moral authorities, Pope John Paul II, not only approved of transplantation but even called it “a gift of oneself” and pointed out that this gift was inextricably linked to love of one’s neighbour and extolled the gospel of life (John Paul II 1996). But the moral ambiguity concerning transplantation has more dimensions than just the religious one. One contemporary Polish philosopher has argued that transplantation is a modern form of cannibalism (neo-cannibalism): “the classical cannibal incorporates part of the corpse by eating it whereas the neo-cannibal incorporates it by means of surgery” (Wolniewicz 1991). The scarcity of donors (in this case, of kidneys from either living or dead donors) is probably also related to society’s negligible information concerning patients’ often dramatically poor quality of life and their constant struggle with the passage of time and impending death. Awareness of this struggle can be gained by observing the everyday lives of patients with final renal failure. The need to popularise this knowledge is what urged me to analyse these problems.

Renal failure is the worst consequence of acute or chronic kidney destruction. It is a condition in which the kidneys lose their capacity to regulate and maintain normal homeostasis in the organism, partly or completely. The disease is insidious. For a long time there are no symptoms and symptoms do not appear until destruction has exceeded 70%. They are irreversible. In final renal failure symptoms exacerbate as the illness progresses and practically all organs and systems are affected: the nervous system, the alimentary system and the cardiovascular system. In the terminal phase the patient is in a coma (Orłowski 1992; Filipecki 1998). The combination of the initially latent progress of the disease and the ineffective health care system is causing delay in accurate diagnosis. Hence, despite the advancement of the pathological process, the experience of disease trajectory does not begin until the condition is very advanced.

Treatment involves a rigorous and troublesome diet (e.g., limited intake of salt, animal protein and fats and sometimes even fruit and vegetables along with the dramatically limited intake of fluids) and dialysis (“artificial kidney”), whose purpose is

to remove the products of metabolism which are retained in the body. In Poland dialysis is conducted in special centres (and therefore requires time-consuming travelling) and is a source of discomfort and stress for the patient. Patients in dialysis must accept not only the actual treatment but also many additional, cumbersome interventions such as the need to create a special arteriovenous fistula, painful injections, fatigue, immobilisation lasting many hours, an unnatural situation, and awareness that one's survival depends on the efficiency of the medical apparatus. All this is a source of great psychological stress, which is difficult to cope with and may lead patients to rebel, discontinue therapy or even attempt to take their lives (Wojtasiak 2004).

Renal failure, particularly its final stage, is a serious condition. It greatly reduces the patient's quality of life and requires many modifications in the patient's own routines and those of the family. Studies of families, and particularly spouses, of dialysed patients revealed deteriorated socio-economic status, depleted role functioning, reduced socialisation, sexual disturbances, stress, and (frequently) elevated depression (Soskolne & Kaplan De-Nour 1989). Family members' own temporal rhythms and everyday practices must also be considerably modified. For example, the patient's need to observe a complicated diet means that meals must be prepared separately for the patient and the rest of the family and shared mealtimes, a factor which has traditionally contributed to family integration in Poland, are often forsaken.

Referral for haemodialysis is a pivotal point in trajectory organisation. This procedure is not just a simple consequence of the progression of the illness or a standard treatment procedure. Since it is still scarce, its availability to certain groups of patients (e.g., older ones) may be restricted, especially in small localities. Even if they are being dialysed, patients have a higher risk of death. They could be rescued if they had kidney transplantation but this, statistically, is even less accessible. At this point, one of the paradoxes of temporal asynchrony becomes evident. Waiting time lengthens but the same time, measured in terms of progression of the disease and possible demise, quickens. This paradoxical experience makes patients and their families even more anxious and may mark a crisis in the illness trajectory.

When haemodialysis finally begins, the patient experiences yet another temporal asynchrony—between biographical time and the time of daily, medical routine (Fischer 1982). Each dialysis last about 4 to 6 hours (depending on the equipment and the patient's condition), not counting the time needed to prepare for the treatment (measuring blood pressure, basic blood tests), waiting to be hooked up to the apparatus or the time needed to get to hospital. (Patient transport ambulance collects patients from different places to bring them to the dialysis centre. This way, patients take several extra hours to travel to and from dialysis). Some patients feel tired after the dialysis and cannot resume their routine activities immediately. We may say that for many of them three days a week are almost entirely devoted to dialysis. This makes it difficult to plan one's present and future life. Treatment which lasts many hours and is repeated three times a week is the central feature in the patient's agenda and other tasks must be subordinated to it. This procedure, whose purpose is to save and prolong the patient's life, is also a time of passivity, inactivity and immobility (the patient must stay in a reclining position and can only shift position inasmuch as this

does not alter the position of the needle injected into the fistula). And the patient knows that this will last to the end of her life or until she receives a transplant. This experience of wasted time leads to the reflection: one must waste time passively to save the time of life. For many of these patients the rhythm of life is divided into two distinct periods: life prior to dialysis and life with dialysis, past life and present life.

If we look at patients' time load and the number of hours they must spend at the dialysis centre we should once again take a glimpse of the health care system in Poland. Not all dialysed patients have absolute indications for haemodialysis in specialised centres. The medical sciences know about such a method as peritoneal dialysis. This form of dialysis may be conducted in the patient's home and self-operated. Patients using this method of dialysis feel much more independent and their illness trajectory is very different. However, patients in Poland have practically no choice of method. It is hard to say exactly why this is so, but it is worth to indicate, that more and more haemodialysis units in public hospitals are being privatised and owned by the doctors. Therefore, they might be materially interested in the number of patients being treated there. Hence, haemodialysis and many hours spent in dialysis centres are a stable element of patients' daily lives.

On the days between the dialysis the patient is more energetic and active. She can work, study or pursue other tasks, i.e., live "normally." This is not illness-free time, however. The patient must diet, control fluid intake, take medication and comply with the entire treatment regime. In other words, her life is focused on the illness. Many dialysed patients identify with the sick role completely and quit work. Since they have to stay in touch with the hospital in which they are dialysed (and temporary change of centre is difficult for organisational reasons), their lives, leisure time and vacations are limited to places near the dialysis centre. Thus, not only their rhythm of life but also their place of residence is subordinated to their illness, all the time.

Patients differ in their acceptance of life with dialysis and their coping strategies. Some, especially younger ones, revolt or break down, some accept their new lifestyle passively and still others seem to tolerate it without undue stress and accept their social status of "a seriously ill person" with all the consequences, but also with all the due privileges (exemption from various chores, receiving disability pension etc.). Those who are determined to overcome their malady begin to see it in a new light: it evokes courage or even heroism. Some patients know that their present life, supported by dialysis, is transitory and "borrowed." The perspective of their life is shortened. And although our medical system knows of several cases when people lived for over 20 years in dialysis, this optimistic scenario is clouded with anxiety, frequent reflections about death and the awareness that such a temporary strategy as dialysis will not radically cure them or prolong their temporal perspective. They are therefore confronted with the values they attribute to life and with the passage of time.

Even if symptoms are successfully eliminated and the patient does not suffer physically, awareness that illness is progressing forces the patient to cope with this fact. In order to cope with the prospect of inevitable deterioration and curtailed life span, many patients resort to various conscious coping mechanisms and unconscious defences. They may repress the threat, deliberately control it by intellectualising their

experiences or deny uncomfortable thoughts. These mechanisms are typical for many life-threatening diseases and are well-discussed in the literature (e.g., Weisman 1972; Rando 1984) so I will not go into them here. As far as the present discussion is concerned, it is worth noting, however, that many of these mechanisms involve the specific transformation of time: it is either subjectively drawn out or its measurable passage is ignored. This can be achieved by adopting strategies called “temporal orientations” (Tarkowska’s term; cf. Tarkowska 1987). The first of these orientations may involve intensification of the present. The patient who chooses this orientation actively focuses on current affairs without looking back or forward. He may choose a future orientation and focus on arranging important business (personal, professional, family, and property) which he will not be able to take care of later because he anticipates that his illness will progress, in which case he abstracts from present troubles. Finally, he may focus on the past—on past memories and experiences when his able body was not a source of suffering and everything was easier and safer (Ostrowska 2005). Each orientation processes the objective time of illness and distress into subjective time, invests it with meaning and value and stretches it out, reducing the experience of stress and tension.

Transplantation can rescue the patient and give him new time. Analytically speaking, it can begin a new trajectory. Transplantation of a healthy kidney from a live donor<sup>2</sup> offers the best prospects but more often transplants are obtained from corpses. Even that, the persistent shortage of organs, including organs from dead bodies, is causing high mortality among patients awaiting transplantation. Hence the new time to live is not something every patient will enjoy with equal probability. Current transplantation policy takes several factors into consideration, e.g., immunological matching criteria (blood group, tissue compatibility) and indication urgency (the patient’s clinical condition), it also considers the age limit for the transplantation procedure (children under 12 years of age have the highest preference; Lasota-Łyszcz 2004). Older patients have less chance of survival or—if they are given a transplant from a corpse—receive an older organ thus reducing their hope for a long life. Non-medical criteria also take into consideration the transplant waiting time and the distance between the recipient and the donor. All the essential examinations and transport of the organ must be completed within a few hours. This involves another form of time pressure. Waiting is replete with stress, disappointment and crises experienced by the patient herself and her family that are also distressed and waiting. Too long a struggle with time means not only symptom exacerbation, it may also lead to mental crisis, in which case the patient will lose the motivation and will to live.

On the other hand, successful transplantation will not always end the illness trajectory either. The organism detects the transplanted organ and tries to eliminate this “alien body” by activating its defence mechanisms. Immunosuppressants, administered to reduce this risk, may have other adverse effects. They are not always effective either and the organism may still reject the transplant or else the new kidney may be

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<sup>2</sup> Kidneys are paired organs but one is sufficient to maintain adequate homeostasis in the organism. In Poland kidney transplants are obtained from genetically or emotionally related persons (np. współmałżonków). Unrelated donors are much less likely to be immunologically compatible.

destroyed by the same pathological processes, which destroyed the original kidney. Whatever the records of survival for renal transplantation patients we know that it is impossible to make predictions for individual patients. Practically speaking, the transplant may cease to function at any moment.

The decision to take a transplant and receive “someone’s” organ triggers new psychological and emotional processes, which may be viewed as an independent trajectory. If the transplant is taken from a dead person, the patient’s thoughts centre on the deceased (who was he/she and how did he/she die) and on his/her body whose part will now become part of the patient’s body. The patient is grateful to the donor who helped to save his life although this gratitude may be marred (at least in the initial phase of the trajectory) by the (sometimes repugnant) awareness that one is containing “a bit of a corpse.” The feeling of gratitude or even indebtedness is more intense if the donor was a live person (usually a family member). However, the gift of an organ is difficult to reciprocate and can be the cause of so-called tyranny of the gift. Katarzyna Kowal who has studied the decision-making process in people who are considering organ donation (Kowal 2007) demonstrated that the incessant and powerful urge to express one’s gratitude may considerably limit the autonomy of the donor and his/her family. The specific symbiosis between the recipient and the donor attests to their close emotional and bodily ties but may also be a source of distress. Additionally, the patient begins to worry that the gift and sacrifice may be wasted if the transplantation is unsuccessful. On the other hand, a close relative’s refusal to donate an organ may trigger anger and resentment although these feelings are usually hidden (Kowal 2007).

Initiation of the process leading to organ transplantation from a live donor is often delayed because there are no clear procedures. Naturally, it would be hard for the patient to begin to talk with his/family about possible donation. Doctors also have difficulty suggesting it to families and they usually advise that the family first consider taking advantage of the opportunity to transplant the organ from a dead donor. Families in turn may feel an unverballed but tangible pressure to donate an organ to their sick member. They may offer to donate the organ but they may also “escape” by avoiding intimate relations with the patient who, they feel, is putting them under pressure. Of course the quality and dynamics of such decisions depends on how emotionally close the donor and recipient are. Parents who offer their organs to a sick child make the most spontaneous decisions. But even the deepest affection and most noble motives cannot guarantee that the transplantation will succeed.

Transplant rejection begins a new crisis in the illness trajectory. The patient feels worse, must learn to live with dialysis once again, experiences mental breakdown but also has some hope of a new, successful operation, even if reflections on the previous aborted operation cast a shadow on this hope. Reduced hope shortens the temporal perspective; the patient no longer thinks about and makes plans for the next few years or months. The only tangible horizon is tomorrow. In many cases, however, the first or second transplantation is successful and hope, euphoria and fear of return to dialysis give way to a period of stabilisation and faith in the permanence of the new quality of life. Younger patients usually seek employment, start a family or have children, “live

normally.” And although the patient who has a transplant must remain in the care of the transplantation centre and monitor the functioning of the transplant regularly, successful transplantation means regained quality of life.

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The time of individual distress, waiting and hope can also sometimes be expressed in macro-social terms. Medical statistics use such collective indices as the number of years of life lost due to premature death, the number of years lived without illness or disability or the cost of every “additional” year of life gained due to the application of medical procedures. The individual human struggle with illness takes the form of statistical data which are analysed at summary, generic level. All these data and indices, whose main purpose is to evaluate the functioning of medical systems, are based on the passage of time: time with illness or time without illness. In other words, the time of individual experience is translated into social or statistical time. Time thus conceived is often an instrument of social policy, an argument in favour of the quest for, and implementation of, desirable solutions. This justifies the decision to end this discussion of time in illness with the following question: what are the chances of prolonging the life of patients with final renal failure in our country?

In Poland, about 80% of recipients live five years or more with a transplanted kidney. The longest registered survival for a patient whose kidney was obtained from a living relative is 42 year, the longest registered survival for a patient whose kidney was obtained from an unrelated donor is 28 years and it is 34 years with the kidney obtained from the corpse (Poltransplant 2007). As I said before, the most desirable procedure in final renal failure is kidney transplantation. Analysis of the scale of transplantations in Poland suggests, however, that the chances that patients who qualify for organ transplantation will actually live to be operated are very limited. Although Poland occupies an intermediate place in Europe as far as the number of organs taken from corpses is concerned, we have one of the last places as far as organs from live donors are concerned (Kowal 2007). This is so despite the fact that we have many superb specialists and adequate legal regulations and the funding of expensive operations by the budget is not an issue. Yet about 50% of patients with renal failure die in Poland (Poltransplant 2005). The experts agree that the main obstacle is resistance of living donors and relatives.<sup>3</sup> The scarcity of transplantations from relatives in Poland is particularly intriguing considering that Poland is thought to be a mainstay of pro-family values. For many patients this means a life subordinated to time-consuming and tiring dialyses.

The scarcity of transplants has stimulated research on the possibility of using organs obtained from transgenic animals or stem cells capable of transforming into the cells of various systems and organs. It will still be a long time before these technologies are implemented, however, and they are replete with ethical dilemmas which must

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<sup>3</sup> This problem surely deserves a separate publication. It is worth mentioning the existing research on Polish society's attitudes towards transplantation by e.g., B. Pawica and M. Szczepański (2003) W. Derczyński (1995, 1997, 2003) and K. Kowal (2007).

be solved. Once again, time is working to patients' disadvantage. Meanwhile, the prognosis for 2010 is that about 25 thousand people will have final renal failure in Poland. The fact that the population is ageing only makes things worse.

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*Biographical Note:* Antonina Ostrowska, Professor of Sociology at the Institute of Philosophy and Sociology, Polish Academy of Sciences. Her researches and publications focus on socio-cultural aspects of health and disease, lifestyles and social inequalities. She is the author and co-author of a dozen or so books dealing with this subject, eg: *Kultura zdrowotna społeczeństwa polskiego* [Health Culture of the Polish Society] (1991), *Syndrom niepełnosprawności w Polsce. Bariery integracji* [The Handicapped Syndrome in Poland. Integration Barriers] (1996), *Śmierć w doświadczeniu jednostki i społeczeństwa* [Death as an Individuals's and Society's Experience] (1991, 1997, 2000), *Styl życia a zdrowie. Z zagadnień promocji zdrowia* [Lifestyles and Health. Some Health Promotion Issues] (1999), *Seks po polsku. Zachowania seksualne jako element stylu życia Polaków* [Sex the Polish Way. Sexual Behaviour as an Element of the Polish Lifestyle] (2003), and an editor of many collective works and articles on science.

*Address:* aostrows@ifispan.waw.pl