

‘I Was a Model Student’: Illness Knowledge Seeking and Self-care Among Finnish Kidney Recipients

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Abstract

The customer based ideology currently in use in the Finnish welfare state, as elsewhere, has transformed health care. Responsibility for health, that used to be lodged within society, has become the responsibility of the individual. Self-care is part of this growing trend, where there is an inherent assumption that informed patients are more capable of making decisions about their medical regime, which in turn empowers them. Finnish kidney transplant recipients are, through various sources and forms of health information, encouraged to follow the moral imperative of engaging in certain types of health maintaining behaviour that safeguards the transplant kidney. Being informed and sharing illness related information with peers is a manner of showing gratitude towards the state; a way to, in some fashion, reciprocating the valuable gift of a kidney through caring. Taking my lead from Mol’s (2008) notion of care as a practice, as something that is done by all those involved in giving care, I ask how knowledge seeking and sharing on illness can be a form of self-caring. The aim of the article is, thus, to discuss what role illness-related information has in the process of caring for kidney failure. The data consists of in-depth interviews with 18 kidney transplant recipients narrating their illness trajectory, and additional information solicited on a number of central themes, two of which were the access to illness-related information and involvement in peer support activities.

Keywords: Transplantation, social identity, illness, health information, communication, care, reciprocation

Introduction

In the Finnish welfare state, as elsewhere, policy making has been steadily moving from preventive health care, where responsibility for health has been lodged within the health care system and the professionals working within this system, to becoming the responsibility of the individual, turning patients into ‘customers’ of the medical establishment. Discussions in Finland circle around the cost-effectiveness and efficacy of healthcare services through a process of privatisation, auditing and individualisation of service delivery (Anttonen 2002; Wrede & Henriksson 2003; Helén 2008; Ollilla & Koivusalo 2009). It is no longer an issue of medical professionals directly controlling individuals to reduce health risks, but of individuals exercising self-regulation of their bodies and of how they act, coupled with the emergence of individual obligations (Miller & Rose 1990; Castel 1991; Higgs 1998).

Issues such as patient empowerment and self-care often feature in the discussion on patients as customers, as a way of indicating that taking responsibility for one’s own health and exercising the right to choose is positive for patients. This line of reasoning has, however, been criticized and questions raised regarding the purported benefit to service receivers (see e.g. MacStravic 2000; Smith 2002; Salmon & Hall 2003; Salmon & Hall 2004). When taking into account the whole context of the lived reality of chronic illness and the varied situations in which patients and their care-givers must assume responsibility for their own health, it becomes clear that not all patients are ready or capable of assuming this responsibility. Many expect to be *cared for* and given advice by health care providers. Mol (2008) wants to draw our attention to the fact that rather than patients *purchasing* care as consumers of a service, it is an issue of care being something that is enacted through various practices by patients and all those involved in the collaborative effort of caring for the patient. The ailing body is actively attended to through a multitude of practices in numerous contexts and situations. What one finds when looking at the lived reality of illness is that the process of caring is far more intricate than a straightforward market-like relationship.

This becomes all the more significant in the case of chronically ill patients that have a long-term relationship with the health care system, for example patients suffering from kidney failure. They are in a position of dependency and as they cannot be cured their care needs to follow a sociomedical model (Comelles 1988 quoted in Masana Bofarull 2010), based on a broad definition of self-care that includes all practices – medical, logistical and social/emotional – taking place in both the clinical context and outside of it (Illich 1976). They live with bodies at risk, first through the failing state of their kidneys, and later in post-transplant life through the health complications resulting from immunosuppression use. The majority of persons who fall ill have very scant knowledge and understanding of human anatomy and on how medications, their side-effects and treatments will affect

them (Simpura 2000). Still they are expected to take responsibility for their illness and seek knowledge about it. This is expected behavior of good patients.

In this article I will focus on how patients I interviewed as part of a project aimed at studying the meanings of donated kidneys and the experiences of organ transfer¹ among kidney transplant recipients in Finland talk about and make use of the information they have been given or actively sought on their illness. The question of illness information seeking was but one theme covered during in-depth interviews.² Individuals that participated in this study were recruited through a national and local level patient organisation, and were thus what could be termed as 'active' patients in that they attended events organised by these organisations. They actively sought to educate themselves on the various aspects of their illness and to create social bonds to other patients suffering from kidney failure, to share information on illness. Some of them were peer supporters and experts-by-experience that had received official training by the national level patient organisation, the National Federation of Kidney and Liver Diseases. They trusted the expert knowledge of specialist doctors and were overall satisfied with and grateful for the care they had received. Instead of viewing kidney failure as a restricting condition and patients as passive sufferers I view them as actively engaging in their illness, seeking ways to learn to live well with kidney disease.

A striking aspect of the illness trajectory of kidney failure, like with many other chronic illnesses, is the extraordinary amount of information patients receive and need to be familiar with in order to live well with their kidney disease and the transplant kidney. My hypothesis is that receiving information to be able to make choices about one's medical treatment is an integral part of the caring that patients and medical professionals are involved in. What is central is how caring is intertwined with the communicative process. Knowing and talking about illness, and applying this learning, are forms of caring about one's failed kidneys. It is a manner of strengthening a shared identity based on failing biology through the sharing of information on this condition and the provision of mutual support – as such it is a form of biosocial engagement.

Being Informed

It is thought that the purpose of providing patients with information on their medical regime is to empower them to take charge of their illness and to make decisions about treatment options; to give them a choice (Salmon & Hall 2004). Studies on how cancer patients use information have indicated that they do value being given information on their illness, but that the communicative process was for them primarily a manner of building relationships with doctors and of building hope (Salander et al. 1996; Salander 2002). In many cases it was not used as a basis for decision-making. For them, decision-making was about coming to terms with their illness and following the recommendations of the doctor, whose

knowledge on treatment they trusted. Making a decision was not equivalent to having a choice (Salmon & Hall 2003; Salmon & Hall 2004; Wathen & Harris 2007).

Mol discusses the issue of choice extensively in her book *The Logic of Care* (2008). Her argument is that the process of informing patients is not something neutral and unidirectional, on the basis of which the patient will make a rational choice about care. Health/illness informing processes are never free from power and knowledge relationships. By using this logic, information is seen as more important than care and by focusing on choice we fail to see how care is actually practised. The ability to make choices depends on a multitude of factors such as age, gender, type of illness, class, level of education and also on the specific situations that unfold as a result of the illness; in illness bodies are unpredictable so situations can change unexpectedly (Ibid: 18). Care, to Mol, should be seen as an on-going process, built around the principle of relationality and collaboration. All those involved in the process of caring for an ill individual strive through various practices, through *doing* together, towards the best possible outcome for the patient – an improved quality of life (Ibid: 75).

The process of informing about illness is thus not a neutral practice, but rather a process where forms of ‘situated knowledges’ (Haraway 1991) are exchanged. The knowledge that is imparted needs to be flexible and take into account the needs and specific illness stage of the receiver of information. Biomedical knowledge is often complemented and enhanced through the use of experience-based lay knowledge and emotional support that peer support groups can offer. Practicing care through shared experiences and information is a way of building identity as a group or community. For kidney patients this identity is not contested, as diagnosis and the treatment path is more or less clear and there are official guidelines on how they should be treated. Being informed is more than just getting information; it is also about engaging in certain practices as a result of this information, of participating in *doing* one’s illness and that of others through mutual advice, listening and understanding.

Why then do patients need to get or seek out information on their illness? In Finland the right to information is clearly stated in the Law on the Position and Rights of the Patient (Finlex 1992/785); ‘the patient has a right to receive information on his or her state of health, the meaning of the treatment, the various treatment options and their effects and other matters that are of significance when taking decisions on the treatment. Information should not be given against the will of the patient.’³ It also has the pragmatic aim of helping patients understand their illness better and care for themselves. Within specialised medical care, like the transplant sector where treatments are expensive,⁴ it makes economic sense to safeguard the investment the welfare state has made in the patient. Naturally, there is simply also the desire to reduce the patient’s suffering. Being cared for does not exclude a need to be informed; it is, rather, an integral part of the care process.

Providing illness-related information is something that enables the patient to take precautions and act in a way that makes it easier to live with chronic illness; in short, of being a good patient. Some patients actively educate themselves on their illness and the therapeutic process involved. Being informed may give them a degree of control in a situation of overall uncertainty that chronic illness entails. Others again are not active knowledge seekers because they believe it is the doctor's responsibility to inform them about matters related to their illness, that they are weary of challenging his or her expertise and fear transgressing the boundaries of their patient role (Henwood et al. 2003). Some patients prefer to know less about the medical details of their condition as this causes anxiety (Leydon et al. 2000). What is central in the process of informing is that it is *done with care*, that it tends to the specificities of each individual care process (Mol 2008: 79).

Suffering from Kidney Failure

Individuals suffering from chronic kidney failure enter the realm of being diagnosed in varying ways. For many it is an issue of the illness being 'hidden', sometimes for decades in their body. The underlying causes are usually hereditary diseases, a complication resulting from having type 1 or 2 diabetes, cardiovascular diseases or an improperly treated kidney infection earlier in life. In rare cases the diagnosis of kidney failure may come dramatically as a result of poisoning (Levey et al. 2003; Munuais- ja maksaliitto 2011). Provision of health care services follows the welfare state model in Finland.⁵ In principle, this ensures that all individuals are treated equally within the health care system. For kidney patients this means that those who fulfil certain criteria will receive a transplant⁶ and all costs related to the process are covered almost entirely by the social security system. This is also linked to the fact that the current care recommendations state that the proper form of care for acute kidney failure is dialysis (the artificial cleansing of the impurities in the blood through the use of a machine), followed, in most cases, by a transplant (Käypä hoito 2011). Chronic kidney failure can be treated through changes in diet and use of medication in slowly progressing cases. The illness trajectory will usually stretch over a long period of time, depending on when the condition is diagnosed. For most patients it is thus an issue of having a long-term relationship with specialised medical care and regularly meeting with a nephrologist in a regional hospital.

Last year a total of 164 kidneys were transplanted and about 3500 patients are living with an organ transplant in Finland (Scandiatransplant 2012). Demand overrides the supply in the market for transplant organs and the prognosis is that this number will increase with the rise in diseases like diabetes type 1 and 2. At present diabetics are the largest group of patients needing kidney transplants; around 25% of all recipients (Salmela et al. 2004). Finland has relied mainly on deceased donation as the percentage of live donation is considerably lower than in

other European countries. For example, as compared to Norway and Sweden, where live donation comprises around 50% of all donations, this number is 3-5% in Finland (Salmela 2010: 2556). Recently, Finnish surgeons have been vocal about increasing live donation, which is in line with global trends (Boas 2011).

A national level patient organisation, the National Federation of Kidney and Liver Diseases⁷ actively advocates for the rights and services of kidney and liver patients. They organise public events and lectures, training courses like peer support training or rehabilitation courses at various stages of patients' kidney disease progression (pre-dialysis, dialysis, post-transplant), meetings and discussion groups (both face-to-face interaction and through web-based discussion forums),⁸ production of patient guides and policy documents (either as print material or web-based information) and a member journal that provides information on various aspects of kidney disease. Active contacts and cooperation are maintained between the patient organisation and transplant surgeons, nephrologists and policy makers in order to bring about necessary policy changes that benefit transplant patients. Throughout the history of nephrology and the development of transplant surgery in Finland medical professionals have worked to improve the position of patients. Most central actors in this field have been familiar with each other and close connections between these various actors have been established. The building of a tight knit community has been aided by the fact that all transplant surgery is carried out in one hospital, the Helsinki University Central Hospital.

Sources of Information

Kidney patients can thus easily locate options for self-education and peer-education by consulting the website of the National Federation of Kidney and Liver Diseases or doing searches on the internet. They are provided with a multitude of information throughout their illness trajectory by medical professionals in the form of guides and manuals handed out in a clinical context by medical specialists, nurses, nutritionists or social workers. On the national patient organisation's website patients can download a general guide for kidney patients, guides on physical exercise for patients suffering from kidney failure and on good criteria of care. They can order a cook book and brochures on nutritional issues, the activities of the patient organisation, prevention of kidney disease and use of salt. The general guide provides brief information in clear language on the central concerns of kidney patients; the function of the kidneys, causes of kidney disease, related illnesses, diagnostic testing related to kidney disease, different forms of dialysis, transplantation surgery, emotional issues (psychological coping), self-care (nutrition, exercise), rehabilitation, medications (effects of immunosuppressive medication and use of other medications), social security and personal stories of kidney patients. The information provides a great amount of detail on how the biological functions of the body are impacted by kidney failure. Similar issues are taken up

in rehabilitation courses organised by the patient organisation or by the Social Insurance Institution of Finland and may be the subject of lectures given in events organised by the local chapters of the national patient organisation.

Seeking information on one's illness implies that one has an active, positive attitude towards learning and a willingness to take responsibility for one's own health (see also Plough Hansen, Tjørnhøj-Thomsen & Johansen 2011). This learning takes place in various contexts, such as events organised by the patient organisation (trips, lectures, sporting and cultural activities), clinical environments and in the patient's home through broadband communication, by reading patient organisation magazines, or through personal communication with other patients. The amount and intricacy of this information is staggering. The adjustments needed to be made in the personal lives of patients, in terms of diet, physical exercise and ingestion of medications are complex and demanding. It is understandable if some patients simply cannot manage this information overload and expectations, especially in a situation of being vulnerable. The help of family members is crucial as they are a vital support in this process.

The hegemony of the knowledge of experts is still strong in Finnish society (Tupasela 2008 & 2007), although there is talk of citizens' participation and a burgeoning trend valuing experiential knowledge. The use of experts-by-experience (*kokemusasiantuntija*) has become a standard practice in patient organisations. One indication of the increased valuation of this type of knowledge in my study is the recruitment, training and use of patients as experts-by-experience by the National Federation of Kidney and Liver Diseases.⁹ They receive training to acquire particular skills in talking to other patients and advising them on how to solve medical or social problems relating to their illness.

One's social identity as a patient is strengthened through learning and sharing of experiences, by patients using each other as a therapeutic resource or by telling of their experiences to health professionals. Events where illness information is shared function as a kind of therapeutic community and moral economy of its own (cf. Guell 2011). The ultimate goal of this learning process seems to be the maintenance of a normal life where normality is defined as the need to be an active, responsible and free person in control of life (Rose 1999). The moral discourse of this social action is clear: a proper, 'good' patient should seek to live in a manner that safeguards the transplant so as to prolong its life and the life of the patient through engaging in exercise, ingesting the right nutrition, entertaining good inter-personal relations, and being compliant and well informed in terms of medical therapy use.

Patient Experiences of Being Informed

During in-depth theme interviews kidney recipients were asked whether they felt they had received sufficient information on their condition from health care pro-

professionals. The overall response was positive and most felt that information related to their illness and the treatment had always been readily available. They saw the acquiring of information as a shared responsibility; they both expected the experts to volunteer this information and realized the need to take an active role themselves.

When asked whether they had been informed about and given the opportunity to choose between different treatment options, most notably in their case the choice of dialysis, some remembered that they could choose, whereas others had a vague recollection of these situations. In most cases they were presented with options and explained how each option would affect them in their everyday life (frequency of treatment, type of equipment, types of structural changes needed to be made in the home, amount of supplies, degree of freedom afforded, place where treatment would be administered).¹⁰ They also received information on immunosuppressant medication. Here doctors simply informed the patient which medication they would be given. In this matter patients had no choice.

Trust and Continuity in Communication

It is not only an issue of imparting and receiving information, but equally important - if not more important - is the manner in which the information is communicated. Recipients desire that a trusting and caring relationship is built between them and health care professionals. Being informed is part of a broader process of creating a new and shared illness identity based on making the illness known to oneself, as part of a process of familiarisation and normalisation.

Henri's kidney failure did not come as a surprise to him as he had known since childhood that a hereditary disease would gradually destroy his kidneys. He was well prepared for his need for treatment. In 2002 he received a transplant, having spent a year in dialysis. Henri says the following about the information he received from his regular doctor;

In dialysis the good thing was that I had a doctor who had been a nephrologist all his life. He was a sixty year old gentleman and I learned to trust him. What I told him he took seriously and had it investigated. He would prescribe medications and then he would explain why these medications were given and not other ones. He was a trustworthy person. [Does it have to do with the long-term contact? I ask] Yes, and then that the more a doctor is specialised the more I trust him. I value to no end the surgeons at the surgical hospital. They were very modest and down-to-earth and ordinary, but they had an immense amount of expertise. (Henri, May 2010)

Due to the, in most cases, long-term nature of the illness trajectory in kidney failure patients will see the same specialist (nephrologist) sometimes for decades. Treatment and patient-doctor communication in specialist care is, according to the kidney patients that participated in this study, better than in general care. In addition, the personal qualities of the doctor are important. The fact that the doctor was modest and down-to-earth served to reduce the communicative distance between Henri and him, strengthening the trust between them.

Petri, a university educated man in his early 30s who has received two kidney transplants, after a long and bitter experience of problems with his kidneys and his first transplant, talks about the importance of being informed in order to be able to understand what the nephrologist was telling him about the state of his kidney failure:

I gathered a lot of information. I strove to read medical articles in both English and Finnish about all of this [kidney disease] because I wanted to be well-informed about first of all what the lab results said, because all of a sudden there came a lot of new things that I had never heard anything about. I don't like that I am told things that should be significant to me and I don't know what they are talking about. So I found out [what it was about] and I also asked the doctors what things meant. (Petri, April 2010)

He wanted to be able to engage in a dialogue with his doctor and wished for continuity of communication by requesting to always be cared for by the same doctor. In the beginning of his treatment period the hospital would send him to different doctors every time and it annoyed him, also because his diagnosis and subsequently his treatment were delayed as they could not pinpoint what was wrong with him. Being informed for him meant having a better knowledge of what was going on in his body and being able to interpret the various symptoms of kidney failure. After receiving his diagnosis he wanted to ensure he was in control of his condition and the treatment of it, to the extent that this was possible.

I said I want to go to this guy [the nephrologist], that I always want to go to this guy and they always arranged it so I could see him. At some point he said to me that go with what you feel like. Take more or less blood pressure medication. [-] A certain kind of communication level was developed, where he did not have the typical authority role of doctors, but more a kind of situation where an expert tells a person that understands. I thought it was nice that there was a dialogue that led to some kind of result [-] he would ask me something and did not just say that now we will do this. (Petri, April 2010)

Being educated and capable of understanding the medical jargon used by the medical expert was for Petri, it seems, also a matter of prestige. As a university student he was used to reading and discussing complicated texts. He wanted to apply this with his doctor to initiate a dialogue where he could feel more as an equal with the doctor. He wanted his knowledge and insight to be respected and recognised.

In 1978 Ossi received his first of two kidney transplants and at that time patients were hospitalised prior to the surgery at the nephrology ward of the Clinic of Internal Medicine at Helsinki University Hospital. He remembers the manner in which the leading nephrologist of the ward included the patient in the treatment by going through the information in the patient file with the patient:

I noticed when I was moved to [the nephrology ward] how much information can be given to a person about a serious illness. It was the habit of X [the head nephrologist]. He would take your file and come and sit next to you and [he would say] 'let's see you have that at that point [some blood value] and there is the reference value

where it should be at, and you have this and it affects you in this way'. And he would start telling me about all these things in a manner that probably is very clear to the doctors and staff, but not to the patient. He included the patient in the care and when you knew you had that blood value you knew that if I avoid eating that salty food or something like that then it would affect a certain blood value. (Ossi, April 2010)

This particular nephrologist is a legendary figure in the field of Finnish nephrology and has been active in the sector since the beginning of its development in the 1950s (Huhtamies & Relander 1997: 53). His habit of keeping patients, not only informed about the progression of the illness, but also increasing their understanding of their condition, was something he passed on to his students and the nursing staff. Increasing understanding was at this stage of the specialisation of nephrology tied to enabling patients to come to terms with their illness and to act in a manner that was beneficial to their own wellbeing. Patient involvement in treatment was in the 1970s still not very common.

Needing or Not Needing to Know

Receiving the diagnosis of kidney failure came out of the blue for Eila and it threw her into a state of shock. At first she experienced a period of denial and refusal to come to terms with the diagnosis, but gradually came to learn what her illness required her to know in order to act in a manner that was best for her and for the trajectory of her illness. After spending two and a half years in dialysis Eila received a transplant in 2006:

I really had to study what types of foodstuffs are in different foods, where there is phosphorous, where there is potassium, where is whatever I am not allowed to eat. I simply did not know what I could eat and the nutritionist tried to teach me. But I was anyways totally bewildered about what I dare put in my mouth and my family was bewildered. [-] All these types of things entered my everyday life. I was a model student. Underneath my seemingly brave and matter-of-fact manner of dealing with the situation was a dreadful fear. I always tried, that whatever I understood that they told me, I tried to realise it right away, down to the very last detail. (Eila, October 2011)

She had to fill out forms and keep a food diary, which she obediently did. The nutritionist gave her feedback on the diary and gradually she learned to understand how and what she should eat. Her quest for knowledge was driven by fear and a need to re-assert some sense of order into a disordered reality. Knowing how to behave to best care for her illness was a comfort and enabled her to do something, to act preventively. In exclaiming that she was 'a model student' she also shows that she is aware that there is an expectation that she should be a 'good student' as this is part of being a 'good patient'.

Kaisu was confused and upset when she was told by her doctor that she suffered from a chronic kidney disease. While driving home from her doctor's appointment she thought her diagnosis meant she would die. At home she wrote him a letter and he soon called her to assure her that she would survive. He told her

about dialysis and transplantation and encouraged her to join the local patient organisation. The organisation and the patients that were active there became a vital source of information to her:

I started to attend the members' meetings and started to listen to those people [other patients], what they had and what they had been through. I knew exactly, I had seen a film there about what happens when the alarm goes and they go to retrieve the transplant kidney and the police was trying to locate the patient and all that, how it proceeds. They even showed the transplant surgery and all sorts of things. I was so full of information that it felt like I knew more than many doctors about kidney transplantation. (Kaisu, April 2011)

Filling herself with information was a coping strategy for Kaisu. It enabled her to envision the process to come and to get first-hand knowledge on this from other patients.

Heikki's kidney failure was due to a genetic disease that he inherited from his father and he knew many years in advance that at some stage he would need to receive treatment for his condition. It took many years before the disease came to the stage of dialysis and in 2003 he received his transplant, but had prior to that lived through several dramatic health related turns in his life due to a brain tumour discovered in 1996. When asked whether he feels he has received a sufficient amount of information about his illness he replies:

Yes, I have received as much as I have wanted to know, because I have not wanted too much information. [Oh, yes, why? I ask] Well, if I was told that this illness will lead to [the need for] dialysis it was sufficient enough information for me. You are probably yourself aware that the more you know the more you suffer [*tieto lisää tuskaa*]. Because of that I really have not wanted to deepen my knowledge [about the illness]. I just know that in our family this is hereditary and there is nothing one can do about it. You just have to accept it and not protest against it because there are things you can do nothing about, things that just happen. This was the type of thing you could do nothing about. (Heikki, March 2011)

The fateful nature of Heikki's condition is something he accepts because he has no other choice. From his comments it seems that it removes the burden of knowing too many details about his illness, of educating himself too much on it. He willingly places himself in the expert hands of doctors.

Sharing Information with Peers

Kaisu says that since she has been given a new life twice (two transplants) she has wanted to give something back to other patients by being actively engaged in the patient organisation and acting as a peer supporter. She stresses that she does not directly want to term it as being a manner of repaying her debt of gratitude for having received the valuable resource of a kidney. She just simply wanted to do something good;

Well, I had knowledge. [-] I had knowledge about what patients had experienced and it is better information than that which is given by a nurse or a doctor. I knew how to tell it [about the illness experience] in the right way. Telling it in the way it actually

happened. A nurse may sugar-coat some things and sometimes, I think, doctors also do this. [So it is more honest? I ask] Yes, it is much more honest. [A first-hand experience? I ask] Yes, it is like that. Regardless of who is ill and which illness it is, the one who has experienced it tells it just like it was. This is where peer support is really important. (Kaisu, April 2011)

Kaisu stresses that the peer supporter should not give any advice on medications; that one should not interfere with information that the doctor is meant to provide to the patient. She says that you engage in conversations about the basic things of life, of how the other person feels, of relationship dynamics and how intimacy is affected by chronic illness in a relationship. Sharing one's experiences and empathically communicating that one understands what the other has been through, that you care about the other, generates a sense of belonging.

What is clear in this quote is that she makes a distinction between different types of information, lay and professional knowledge. She is well aware of the value of lay knowledge and the emotional content of this information because it is based in the lived reality of illness. Lay knowledge should not replace or compete with expert knowledge – it complements it and provides a different, but vital perspective. Kaisu knows how important this type of emotionally and experientially based information is because she has herself benefitted from this type of information during her extensive illness trajectory.

Also Ossi appreciates the role of peer support in his illness. He is a peer supporter and expert-by-experience of the National Federation of Kidney and Liver Diseases, as well as an avid organiser of the local chapter of the patient organisation. An important venue of peer support is the surgical ward of the Helsinki University Hospital¹¹ where all kidney and liver transplants of the country are carried out. Following surgery most patients will spend two weeks in the ward. Before the unit was relocated to a new hospital complex patients were all in one big mixed sex room. They would eat their meals around a dining table in the middle of the room and walk together in the hallways of the hospital and the areas surrounding the hospital:

When you were in the hospital you always had a ward full of people. You got to know new people and that stopped [when you left the hospital]. That is why it is so important to get people to attend the trips [organised by the local patient organisation]. [-] At these social activities the more people talk to each other, then at some stage [they start asking] 'how is your health', and then the other person gets the opportunity to talk about it. (Ossi, April 2010)

The ward of the surgical hospital is a place where particular kinds of friendships are formed and even fictive kin relations (see also Sharp 2006). The first days following transplant surgery patients are placed in a double room and if they have gone through surgery on the same day they assume they have received their kidney from the same cadaveric donor. Some will then name the other recipient their kidney sibling and they may keep in touch with each other to compare experiences on the progress of post-transplant life. Also 'non-siblings' may keep in touch.

Another important venue of peer support, where intimate bonds of friendship may be formed, is the dialysis centre. The majority of patients who have opted to do hemodialysis will go to a dialysis centre to have their care administered three times a week for a time period of five to seven hours per dialysis session. Here they will regularly meet the same patients and nurses, who are equally important sources of information (see Gunnarson 2011).

Protected Information

A young peer supporter Matti, who is actively engaged in the youth section of the National Kidney and Liver Federation, believes it is important that young people can discuss their illness with people of their own age group. It has been difficult for the patient organisations to attract younger patients to join their activities. Matti believes the reason for this is that the activities fail to serve the interests of young people. This is why the internet is such a fruitful way of sharing experiences and information, since it is a familiar and popular socialising method:

Today it is facebook. From there [young people get their information] – that is where they share information. Facebook has been a good source of information and otherwise also, as you are all together [there]. It's very good to get information that way. During courses [organised by the National Federation of Kidney and Liver Diseases] you don't always get enough people, so then through facebook [you can get information]. So, in that sense it has been a very good invention. (Matti, October 2011)

The facebook group is closed and membership can be gained only by being recommended by a member of the group. The restrictive nature of the group is necessary as a means of protecting the identity of the users:

From the very beginning it has in a way been insiders' information [that has been shared]. We have not wanted outsiders involved because we don't want it to be known [who is active in the group] because there are regular medical things [that are discussed]. They [the matters discussed] don't belong to outsiders. When you are feeling bad and you don't know anything about this illness then you can [get information] through there [the facebook page]. The members feel that they want to share certain medical information only within the group; compare forms of care and this sort of thing. (Matti, October 2011)

The privacy and intimacy that a closed discussion forum can provide is an important aspect of inclusion for young people suffering from kidney failure. There is shame attached to illness - they would like to be healthy like other young people. Instead of centering their identity on the illness they try to manage it within their peer group, among people who understand what they are going through. Rather than relying only on the authority of medical professionals they want to create their own forms of knowledge where they can democratically share information with each other and critically discuss what they feel are problematic matters pertaining to the care they have been given.

Matti received his transplant at the age of 16 which meant that it was mainly his parents that sought out and received information on the illness. Regarding his need to get any further information he says:

I haven't needed it that much. Since I have been a peer supporter I have gotten a fair amount of experience from there and then I have asked the doctor if I have had any minor complications. [-] Maybe my parents have read more from some book and like that, but not me. [So, your parents have read up on the illness? I ask] Yes, but I haven't needed to. I guess the illness itself has educated me. (Matti, October 2011)

The idea of the illness itself as an educator is very interesting when considering the issue of knowledge as care. A bodily experience becomes personified in the figure of the illness as an educator. By giving the illness subjectivity and entering into a partnership with it Matti is enabled to care for the illness and the transplant. His bodily experience becomes his mentor and a source of self-knowledge.

Discussion and Conclusion

It is an old truth that information tends to increase awareness and that it may lead to changes in behaviour and to empowerment. This is also an assumption made in relation to information on health and illness given to patients. It is not an incorrect assumption. In some cases being given more information may make patients feel empowered, but this equation is not as straightforward as policy makers want us to believe. Being informed may empower the patient, but, above all, it leads to better caring, including both the self and others. It may be better to talk of simply care or caring, rather than using the term self-care, so as to remove the individualism from the term; because in reality it is a collective, collaborative effort. To return to Mol (2008), it is something *done* together, rather than only involving the self.

Based on what the kidney recipients in the study this article is based on said about being informed on illness, it seems that the most important aspect of receiving information and sharing it with other patients was the manner in which it was imparted; how care is expressed in the communicative process. Key notions that arose in the comments of interviewed patients were trust, endurance (continuity of communication), respect and recognition of different types of knowledge (lay and medical), integrity and inclusion. Patients clearly differentiate between professional knowledge given to them in a clinical context and knowledge based on lay experiences given by other patients. Talking about illness and treatment happens in varied contexts and leads to varied practices, all aimed at improving the patient's quality of life.

Patients talk of the importance of receiving support, of building mutual platforms of communication and exchange of information. They seldom mention the importance of choice, because in most cases they experience that they have no choice. The main priority is *receiving information in a caring manner* that is con-

ducive to trust, recognition of knowledge and mutual respect being born between doctor and patient and between patients in peer support contexts. When medical professionals engage in mutually respectful dialogue with patients the information exchange is a form of caring, because they attend to the specificities of the patient's illness experience, and the shifting contexts and situations that affect it. They listen and offer solutions, using their expertise as a resource because they want to help patients, to both *care about* and *care for* them (see also Good 1994 and Lupton 1997). Informing is a practice that contributes to the process of care.

In peer support contexts patients give out information about their own lives with chronic illness with the aim of helping others facing the same predicament. It is about understanding the other, communicating empathy, listening, giving emotional support and practical advice, and of creating shared practices. It is also information that is located in the lifeworld of the patient – this is a place that other patients recognise and can connect to. It strengthens a sense of mutuality, a shared identity, and belonging to a community that also includes doctors that care well for patients. The high value of this information is based on the fact that it is situated, that is, linked to specific contexts and situations. Context here refers both to when the other, one's peer, experienced it, and the context of the communicative event itself. Contexts for sharing peer based information varies; it can be in the surgical ward, during rehabilitation courses, discussion clubs or during leisure activities such as trips organised by the patient organisation, at home through conversations taking place over the telephone or on the internet. For some young patients anonymity and privacy is important, something that protects them, enabling them to talk more freely about difficult experiences. It allows them to maintain a social presence in the community of young kidney patients without needing to disclose their identity or attend any collective social gatherings (see Hardey 2002).

The use of peer information and sharing of knowledge is for most recipients a form of reciprocation, a way of thanking for the valuable transplant received. What is striking about this form of giving back is that it is directed to other patients (see also Sharp 2006; Shaw 2010). As such it reflects a moral economy that highlights solidarity and altruistic motives directed inward, towards one's own community. Since they have received a kidney¹² (nearly) for free they are engaged as volunteers, without receiving monetary compensation, in the patient organisation peer support activities. It is not directed explicitly to the health care system or welfare state that has enabled them to get a transplant, or to the kin of the deceased donor who have given their consent to the donation.

One must, however also recognise that reciprocation is a feature of the whole system of health care. Although it is a legal obligation to provide patients with information about their illness the practice is also part of an on-going circulation of practices, of giving and receiving care within the chain of care. Kidney recipients heed the doctor's recommendations because they know it is good for them

and they trust the expert knowledge of the doctor. They expect the state, represented as the doctor, to care for them. They also want to show they are good patients. In this sense they are showing gratitude to the welfare state for having received the valuable resource of a transplant and having been given an extension of life. The doctor regularly provides information to the patient so he or she can follow the care regime in the best possible way in order to feel better. Reciprocating by sharing information, experiences and practices among peers contributes to the process of care.

The production of information and knowledge by transplant recipients is still an under-used resource in Finland. Little is written about this resource and, although the patient organisation actively markets peer support services to patients, few use this opportunity. Another factor that contributes to the scant use of lay knowledge is the overall lack of visibility that organ transplantation has as a phenomenon in Finnish society. For example, when new legislation was passed on organ donation in August 2010 there was hardly any public debate on the issue prior to the legislative change. The patient organisation organises public events on the International Organ Transplantation Day, which is one of the few occasions when the general public are exposed to the issue, as well as stories occasionally featured in popular magazines and daily papers. Recognition of the caring potential of information and experience sharing within the transplant community, and particularly in relation to the value of lay knowledge and experiences, would thus be important in light of constant cut-backs made in the health care sector. As consultation times will be shortened to save money doctors will have less time to advise and discuss with patients – less time to provide care through the practice of informing. In this context, patient-to-patient sharing of knowledge and experience will become an increasingly valued resource.

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Notes

- ¹ This is a term used by anthropologist Lesley Sharp (2006), meaning the larger socio-medical process which includes organ donation, procurement and transplantation.
- ² The research that this article is based on is the first of its kind in Finland and is a three year project, 'Solidarity and the Body as Gift – Ethnographic explorations into the social and cultural context of organ transfer in Finland', funded by the Academy of Finland (project number 1131907). The project looks at how donation can be understood as a social and cultural practice through the giving and receiving of transplant kidneys, and specifically investigating the various stages and social relationships that were created as a result of the diagnosis of kidney failure as understood by kidney transplant recipients. A multi-sited ethnographic research approach was used where participant observation was conducted of various events organised by the National Federation of Kidney and Liver Diseases and a regional partner organisation (lectures, rehabilitation courses, sporting events, theme days, discussions of a kidney club, recreational trips for members, and other social gatherings), studying documents produced by the patient organisation and illness stories produced by patients, as well as conducting 18 in-depth interviews with kidney recipients, most of whom were recruited through these two organisations.
- ³ Translated from Finnish by the author.
- ⁴ In 2007 home-based dialysis cost 40 000 euro a year, whereas clinic based care cost nearly twice as much (Inomaa 2007: 27). A transplant operation, though costly, pays itself back in three years.
- ⁵ Following Jokinen and Saaristo (2000) I understand the Welfare State as an actor that aims to provide its citizens with a reasonable livelihood and conditions of life based on equality. Its central tasks are to organize child care and other forms of care services; activities related to provision of housing; health promoting activities; production of educational activities; prevention of unemployment; provision of general infrastructure and income redistribution; and provision of services mainly through income received through taxation.
- ⁶ Central criteria that have to be fulfilled in order for a patient to be put on the organ waiting list is age, progression of the kidney disease (are they in dialysis), that the patient does not suffer from cardiovascular disease, cancer, infections, and excess weight (Saha et al. 2010). In Finland all patients must be in dialysis in order to be placed on the waiting list for a kidney transplant. The usual (minimum) time needed in dialysis before being put on the organ waiting list is 6 months. Waiting time for transplant is on average 2 years, but can range from 1-10 years.
- ⁷ The funding of the organisation is provided by the state and RAY - the Finnish Slot Machine which basically means that citizens themselves provide the funding by playing on slot machines (Munuais- ja maksaliitto 2010).
- ⁸ Internet access is good and computer literacy fairly high in the general population in Finland so many patients would be able to avail of these resources. Of those individuals interviewed for my study the majority had internet access and used it. There are also closed patient forums where mainly young patients discuss their illness and issues related to everyday life.
- ⁹ This category of experts is also used by various other organisations in the health and social services sector. They are defined as individuals who have a personal experience of a certain health or social problem, have received special training and are used in the strategy, evaluation and rehabilitation work of municipalities and other institutions (Kokemusasiantuntija 2011).
- ¹⁰ Patients can choose between peritoneal dialysis (either continuous or ambulatory), that uses the abdominal lining to filter out bodily impurities, or hemodialysis where the patient's blood is circulated through a machine that contains a filter membrane (Alahuhta et al. 2008). Perito-

- neal dialysis is usually done by the patient at home and hemodialysis can either be done independently by the patient at home or then at a dialysis centre.
- ¹¹ The surgical ward moved to a large new hospital complex in the autumn of 2011, but all the kidney recipients that participated in this study had gone through surgery in the old hospital.
- ¹² They pay for the surgery and the time spent in the hospital, but these fees are highly subsidised as part of the welfare state funded social security system.

References

- Alahuhta, Maija, Tuija Hyväri, Marjatta Linnanvuori, Risto Kylmäaho & Heikki Mukka (2008): *Munuaisairaalan hoito* [Care of the Kidney Patient], Helsinki: Edita Prima.
- Anttonen, Anneli. (2002): 'Universalism and Social Policy: A Nordic-Feminist Reevaluation', *Nora*, 10: 2, 71-80.
- Boas, Hagai (2011): 'Where do Human Organs Come From? Trends of Generalised and Restricted Altruism in Organ Donation', *Social Science and Medicine*, 73, 1378-1385.
- Castel, Robert (1991): 'From Dangerousness to Risk', Graham Burchell, Colin Gordon & Peter Miller (eds): *The Foucault Effect: Studies in Governmentality*, Brighton: Harvester Wheatsheaf.
- Comelles, Joseph (1988): 'Acerca de la construcción sociocultural de la cronicidad' [About the Sociocultural Construction of Chronicity], *Jano*, Vol. XXXIV, 808, 43-49.
- Finlex (1993): Laki potilaan asemasta ja oikeuksista 785/1992 [Law on the Position and Rights of the Patient]: <http://www.finlex.fi/fi/laki/ajantasa/1992/19920785> (accessed 2012-01-09).
- Good, Byron (1994): *Medicine, Rationality and Experience: An Anthropological Perspective*, Cambridge: Cambridge University Press.
- Guell, Cornelia (2011): 'Candi(e)d Action: Biosocialities of Turkish Berliners Living with Diabetes', *Medical Anthropology Quarterly*, 25:3, 377-393.
- Gunnarson, Martin (2011): 'Delade erfarenheter eller egen expertis. Att vara dialyspatient i Riga och Stockholm', *Socialmedicinsk tidskrift*, 3, 257-265.
- Hansen, Helle Ploug, Tine Tjørnhøj-Thomsen and Christoffer Johansen, (2011): 'Rehabilitation Interventions for Cancer Survivors: The Influence of Context', *Acta Oncologica*, 50, 259-264.
- Haraway, Donna (1991): 'Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective', Donna Haraway (ed.): *Simians, Cyborgs and Women*, New York: Routledge.
- Hardey, Michael (2002): 'The Story of my Illness: Personal Accounts of Illness on the Internet', *Health*, 6:1, 820-835.
- Henwood, Flis, Roma Harris & Philippa Spoel (2011): 'Informing Health? Negotiating the Logics of Choice and Care in Everyday Practices of "Healthy Living"', *Social Science & Medicine* 72, 2026-2032.
- Henwood, Flis; Sally Wyatt, Angie Hart, and Julie Smith (2003): 'Ignorance is Bliss Sometimes: Constraints on the Emergence of the "Informed Patient" in the Changing Landscapes of Health Information', *Sociology of Health and Illness*, 25: 6, 589-607.
- Higgs, Paul (1998): 'Risk, Governmentality and the Reconceptualization of Citizenship'; Graham Scambler & Paul Higgs (eds): *Modernity, Medicine and Health*, London: Sage.
- Huhtamies, Mikko & Jukka Relander (1997): *Jatkettu elämä. Elinsiirtojen historia Suomessa* [Extended Life: The History of Transplantation in Finland], Helsingin yliopiston historian laitoksen julkaisuja 12 ja Helsingin yliopiston kirurgian laitoksen julkaisu, Helsinki: Hakapaino Oy.
- Illich, Ivan (1976): *Medical Nemesis: The Expropriation of Health*, London: Marion Boyars.
- Inomaa, Petri (2007): 'Kotidialyysilla elämänlaatua ja vähemmän kustannuksia' [Better Quality of Life and Less Costs with Dialysis at Home], 3/2007 *Uumunen*, 27.

- Jokinen, Kimmo & Kimmo Saaristo (2000): *Suomalainen yhteiskunta* [Finnish Society], Porvoo/Helsinki: WSOY.
- Kokemusasiiantuntija (2011) [The Expert by Experience]: <http://kokemusasiiantuntija.fi/> (accessed 2011-02-25).
- Käypä hoito (2011) [Current Care Guidelines]: <http://www.kaypahoito.fi/web/kh/suosituksset/naytaartikkeli/tunnus/hoi50081> (accessed 2011-11-25).
- Levey, Andrew, Joseph Coresh, Ethan Balk, Annamaria T. Kausz, Adeera Levin, Michael Steffes, Ronald J. Hogg, Ronald D. Perrone, Joseph Lau & Garabed Eknoyan (2003): 'National Kidney Foundation Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification and Stratification', *Annals of Internal Medicine*, 139, 137-147.
- Leydon, Geraldine M., Mary Boulton, Clare Moynihan, Alison Jones, Jean Mossman, Markella Boudioni & Klim McPherson (2000): 'Cancer Patients' Information Needs and Information Seeking Behaviour: In-depth Interview Study', *British Medical Journal*, 320:7239, 909-913.
- Lupton, Deborah (1997): 'Foucault and Medicalisation Critique', Alan Petersen & Robin Bunton (eds): *Foucault: Health and Medicine*, London: Routledge.
- MacStravic, Scott (2000): 'The Downside of Patient Empowerment', *Health Forum Journal*, 43:1, 30-31.
- Masana Bofarull, Caterina (2010): 'Self-care Management of Adults with Chronic Illness and Dependency: The Spanish Case in the Context of the New Dependency Law', Sylvie Fainzang, Hans Einar Hem & Mette Bech Risör (eds): *The Taste for Knowledge: Medical Anthropology Facing Medical Realities*, Aarhus: Aarhus University Press.
- Miller, Peter & Nikolas Rose (1990): 'Governing Economic Life', *Economy and Society*, 19, 1-31.
- Mol, Annemarie (2008): *The Logic of Care: Health and the Problem of Patient Choice*, London: Routledge.
- Munuais- ja maksalitto (2011) [The National Federation of Kidney and Liver Diseases]: http://www.musili.fi/fin/munuaispotilaan_opas/ (accessed 2011-11-20).
- Ollila, Eeva & Meri Koivusalo (2009): Hyvinvointipalvelusta liiketoiminnaksi – terveydenhuollon parantamisen tärkeät valinnat, Meri Koivusalo, Eeva Ollila, Eeva and Anna Alanko (eds): *Kansalaisesta kuluttajaksi. Markkinat ja muutos terveydenhuollossa* [From Citizens to Clients: Consumerism in Finnish Health Care], Helsinki: Gaudeamus.
- Rose, Nikolas (1999): *Powers of Freedom: Reframing Political Thought*, Cambridge: Cambridge University Press.
- Saha, Heikki; Lauri Kyllönen, Petri Koskinen and Kaija Salmela (2010): 'Kuka munuaissiirtolistalle? – kriteerit 2011' [Who to be Placed on the Kidney Transplant List – Criteria for 2011], *Duodecim*, 126:2591-9.
- Salander, Pär (2002): 'Bad News from the Patient's Perspective: An Analysis of the Written Narratives of Newly Diagnosed Cancer Patients', *Social Science and Medicine*, 55, 721-732.
- Salander, Pär, Tommy Bergenheim & Roger Henriksson (1996): 'The Creation of Protection and Hope in Patients with Malignant Brain Tumors', *Social Science and Medicine*, 42, 985-996.
- Salmela, Kaija (2010): 'Ovatko munuaissiirrot omaisilta ratkaisu luovuttajapulaan?' [Are Kidney Transplants from Next of Kin a Solution to the Organ Shortage?], *Duodecim*, 126, 2556-2557.
- Salmela, Kaija; Krister Höckerstedt, Ulla-Stina Salminen & Pekka Hämmäinen (2004): 'Elinsiirrot – käypää hoitoa jo 40 vuoden ajan' [Organ Transplantation – Recommended Form of Care Already for 40 years], *Duodecim*, 201:11, 1359-1369.
- Salmon, Peter & George Hall (2003): 'Patient Empowerment and Control: A Psychological Discourse in the Service of Medicine', *Social Science and Medicine*, 57, 1969-1980.
- (2004): 'Patient Empowerment or the Emperor's New Clothes', *Journal of the Royal Society of Medicine*, 97, 53-56.
- Scandiatriansplant (2012): http://www.scandiatriansplant.org/data/sctp_figures_2011_4Q.pdf (accessed 2012-01-09).
- Sharp, Lesley A. (2006): *Strange Harvest: Organ Transplants, Denatured Bodies, and the Transformed Self*, Berkeley, Los Angeles & London: University of California Press.
- Shaw, Rhonda (2010): 'Perceptions of the Gift Relationship in Organ and Tissue Donation: Views of Intensivists and Donor Recipient Coordinators', *Social Science and Medicine*, 70, 609-615.

- Simpura, Jussi (2000): 'Sosiaalipolitiikka piiloutuu, sosiaalivalta verhoutuu', Eija Nurminen (ed): *Sosiaalipolitiikan lukemisto* [The Digest of Social Policy], Tampere: Palmenia.
- Smith, Richard (2002): 'The Discomfort of Patient Power', *British Medical Journal*, 324, 497-498.
- Tupasela, Aaro (2007): 'Re-examining Medical Modernization: Framing the Public in Finnish Biomedical Research Policy', *Public Understanding of Science*, 16:1, 63-78.
- (2008): *Consent Practices and Biomedical Knowledge Production in Tissue Economies*, University of Helsinki, Department of Sociology, Research Reports No. 256.
- Wathen, Nadine & Roma Harris (2007): "'I Try to Take Care of Myself": How Rural Women Search for Health Information', *Qualitative Health Research*, 17, 639-651.
- Wrede, Sirpa & Lea Henriksson (2005): 'The Changing Terms of Welfare Service Work: Finnish Home Care in Transition', Hanne Marlene Dahl & Tine Rask Eriksen (eds): *Dilemmas of Care in the Nordic Welfare State: Continuity and Change*, Aldershot & Burlington: Ashgate Publishing Company.