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Writing the Othered Self: Autoethnography and the Problem of Objectification in Writing About Illness and Disability

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The individual's experience of kidney failure, transplantation, and recovery is not as well documented as might be expected. Often it is written about by outsiders (medical practitioners, care providers, academics), whereas the insider's (patient's) expertise is occluded. This conforms to the experience of many people living with illness and disability. The rendering of people as other (not like the norm) comes at a cost to their humanity. People who are ill or disabled can themselves succumb to a way of writing that simplifies their experience and objectifies themselves. I consider what it means to tell the story of oneself against a background of illness autoethnography, my own story of growing up medicalized and living with end-stage renal disease. I identify three types of illness autoethnography, one of which creates a tension between researcher as agent and researcher as object of research, and compels the reader to constantly realign himself or herself.

Keywords: *autoethnography; disability; illness and disease, experiences; illness and disease, social construction; transplantation*

My new urologist is taking my history. He asks what I do. I tell him I have started my doctorate, a qualitative study of chronic kidney failure, transplantation, and recovery. He pauses and lifts his pen from my life's story.

"What qualifies you to do that?" he asks.

"I lived it," I reply.

He says, "I know, but how can you pursue a degree in this?"

I do not tell him that I am planning an autoethnographic study, because that would take too long to explain. Instead I glibly say I have read on the topic "quite a bit" and have written "for a while." This seems to satisfy him. But it does not satisfy me. Reading should not be considered a better source of information than lived experience. It is just a different one.

I could have told him that recent writing on health, illness, and disability has problematized the extent to which any person can be an expert about the experience of

another person (Foster, McAllister, & O'Brien, 2005; Frank, 1995, 2002; Kleinman, 1988; Marks, 1999; McDougall, 2006; Miller & Crabtree, 2005). When professionals write about patients' experiences of illness, for example, they cannot but represent these experiences through their own professional lenses, however much they might try to do otherwise (Kirmayer, 1992; Sullivan, 1986; Zaner, 2004). The disability movement has been central in reminding us that there is a long history of people living with illness or disability—already othered by society—being othered further through the writings and research of outsiders in general, and health professionals in particular. "Othering" means turning a person into an object of some sort, such as a stereotype or even an object of study. Those whom we study are never quite on the same level as we are. And they are always "not us." Indeed, the oft-used slogan "nothing about us without us" (Braddock & Parrish, 2001; Charlton, 2000) requires researchers to be aware of the centrality of the insider voice: The expert on the lived experience of disability or illness is not the clinician, but the person experiencing disability or illness.

Of course, my planning an autoethnography of kidney failure, transplantation, and recovery raises certain questions. What does it mean to represent illness and disability from the inside, as I intend? Is every first-person,

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insider narrative necessarily an authentic narrative? How do we compare different insider accounts of illness or disability? How do we or can we learn more general lessons from individual stories? Should we? What are the risks of doing so? When I write about myself, do I become two people?

There are many ways of writing about oneself. Autoethnography, as distinct from autobiography, concerns writing about one's own experiences for specific academic purposes (Ellis & Bochner, 2000; Ettore, 2005; Jones, 2005; Reed-Danahay, 1997; Sparkes, 1996; Wall, 2006). I find this takes on a particular piquancy when I am writing from the position of disabled other because first, I do not belong to the mainstream of healthy people, so I cannot pretend my angle of approach is transparent or neutral, as people who occupy a dominant ideology often do and, second, I am writing from a position of less power than mainstream writers in my environment. I am not a medical doctor. My position as author is problematized by my very existence and perceived identity (whether it is my own perception or others'). Because of this, disability studies and illness narratives make fertile ground for examining what it means to write about the self and its context. Moreover, this is why, when autoethnography is discussed, the discussion is to a large extent about writing and what it means to tell a story (Ellis & Bochner, 2000; Jones, 2005; Richardson & St. Pierre, 2005).

In illness autoethnographies the story is particularly intimate and the telling of it can render the writer vulnerable. I am careful who I tell my kidney story to. Illness makes you vulnerable long after it is gone—I do not want to be seen as defective. So I fake normality. I have a lifetime's experience in doing this. No one ever knows what I have been through unless I tell them.

Kidney Failure: My Own and Others'

When I wrote the first version of this article, I was very careful to remove myself and my story from it. I wanted to present a standard philosophical discussion to readers who were not influenced by my condition or circumstances. I did not altogether succeed. One of the areas in which I slipped up was in the use of pronouns. I decided to use third person constructions, but on reading my article and the reviewers' feedback, I discovered I had occasionally referred to myself after all. This happened mostly in the latter part of my article when I was discussing illness narratives specifically. I also discovered to my surprise that the reviewers were not repelled

by this. On the contrary, two did not mention it at all and one openly suggested that I change from relying so much on the third person.

The reviewer who suggested I rely less on the third person suspected that I had a story to tell, although I am certain I made no mention of it in my article. How did she or he know? On reflection, it was obvious. We do not choose our topics accidentally and our motive for researching them is often personal. This is particularly noticeable with research into illness and disability, where the motivation for research from personal history is more readily apparent (Cassell, 2005; Davis, 1998; Ellis, 1995; Ettore, 2005; Frank, 2002; Muncey, 2005; Sparkes, 1996).

My route to my present research started when I was eight months old. I became ill with hemolytic uremic syndrome (also known as Gasser's syndrome or hamburger disease) and grew up with atrophying kidneys. I eventually had a successful transplant at 22. It has taken me 16 years to be able to write about it. In so doing I have begun to untangle what growing up like that meant to me and what it meant to become well—or what I understand as being well. This is the topic of my doctoral research.

Chronic illness has been described as a "well-researched area" (Ettore, 2005, p. 534). For people who do not have chronic health problems, chronic illnesses might all seem the same: you have health problems that persist (and you are not like us who do not have this). However, for those of us who do experience or have experienced chronic health problems, each disease is a different country, with different languages and customs, different laws, different international relations with the healthy. Some chronic illnesses are more symbolically charged than others (Couser, 1997; Sontag, 1978). AIDS and cancer carry an entirely different symbolic significance to kidney failure, although all are fatal if untreated. Very importantly, some areas of chronic illness are better researched than others. In qualitative research, kidney failure and transplantation are underresearched. Let me show you what I mean.

In 2006, approximately 65,000 organ transplants were done worldwide, of which about 45,000 were kidney transplants (Helman, 2007). The individual experience of kidney failure is not as well documented as might be supposed. The bulk of what is written on kidney failure is written by health care professionals for health care professionals and about patients. Most of these studies are of necessity quantitative. A handful attempt to address the psychosocial or ethical issues.

Often this type of analysis will be about organ transplantation in general, with a subsection on kidney transplants, and will often use people's lives to illustrate idea-based issues (Baines & Jindal, 2003; Cherry, 2005; Fox & Swazey, 1978, 1992; Lock, 2002; Machado, 1998).

Very few of the above-mentioned works go beyond the bigger life-and-death issues to the impact on the individual, or stray far into life after the transplant once the most immediate medical crises are over. This is because most of them are not concerned with people as people, but rather with what they represent or with medical processes and what these involve. These works are not about individuals. That is not their purpose. But lives are lived by individuals, just as facts precede theories.

Writing About Disabled Others

Writing about human experience poses a number of conceptual problems for researchers. Writing about people with disabilities amplifies these problems. People living with disabilities or illnesses are often "reduced to the status of malfunctioning bodies" and viewed as "lacking capacity to put forward their point of view" (McDougall, 2006, p. 395). More specifically, they are represented this way: They are squashed into a medicalized narrative. People living with disabilities or illnesses are seen as objects of study and not as agents of study. There seems to be an underlying assumption that such people need to be talked about, but should themselves remain silent as if they do not have anything useful to contribute. They are also frequently the recipients of other people's expertise, not the contributors. This results in their being dehumanized and their unique situations generalized. The individual and the individual's case can disappear.

Allowing patients to talk can yield information that a health care practitioner might otherwise never discover (Kirmayer, 1992; Zaner, 2004). However, this does not happen often enough. I keenly felt the irony, as a patient, that my medical treatment was all about me and the intimate details of my anatomy, and yet I seemed entirely absent from the process. When doctors visited my ward, I would be talked about and talked over as if I were not a sentient being. They would make decisions about me—including which procedures of varying degrees of invasiveness I was to have, and which medications were to be pumped into my system—without once addressing me. They would extrapolate and import knowledge from other cases to mine,

as if we were all extensions of the same circumstance. I felt as if they saw me as a side of beef or an old suitcase, which decreased my confidence in the experience, for I was neither. They relied heavily on my chart, which was an incomplete record of my medical condition and I had to keep interrupting them to correct them.

Outsiders can only ever really be onlookers. They can glean information about what it might be like inside, but they do not truly know. I remember once being told by a doctor that the transplant operation was going to be painful. I asked him how bad the pain would be. He looked at me blankly, and then repeated that it would be painful. We ended up having an altercation about it, which resulted in my learning that he knew it would be painful because he had observed patients experiencing pain, but had no idea how much there would be or what type, because he had not experienced it. The pain I experienced turned out to be quite bad. Many analgesics are excreted through the kidneys and I had to forgo them after my transplant operation, so that I did not compromise my kidney function. He never asked me about the pain afterward, though. It seemed not to be relevant to his work, because he could not treat it. It was, however, relevant to me. Had he been through kidney failure himself, he might have been more compassionate about his patients. This could have augmented his medical expertise.

Disability "seems, often, to exist beyond a barrier of thinking and seeing that encloses disabled people in silence and obscurity" (McDougall, Swartz, & Van der Merwe, 2006, p. ix). The same is true for illness. In addition to this, not all disabilities and illnesses are apparent to observers and not all perceived disabilities are disabilities to the people experiencing them. A person who has been blind for a long time might well be as capable as a sighted person and might not wish to be given their sight (Kurson, 2007). Or they might. While on dialysis at age 21, I worked with a physiotherapist to improve my cardiovascular function. I was feeling better than I had in years. I could run up steps after not being able to climb them at all for four years and really enjoyed my exercise program, until the day she tried to discuss my (as she saw it) "handicaps" with me. I had never seen myself as handicapped and objected so strongly that we never got to the bottom of what those handicaps were. They apparently involved not being able to run marathons. I had never had a desire to run one. My interests were in writing and research. I was not disabled to me, but I was disabled to the expert and so my view was ignored.

One of the ways in which so-called abnormal lives are controlled and normalized is through being written about. These types of narrative use certain narrative structures to control and explain, as well as to help form new identities. A narrative that might heal and restore some of a damaged identity might also conceal some of the complex, messy nature of that identity (Frank, 2000; Kirmayer, 1992). People who do not belong to a dominant ideology or mainstream—particularly those with disabilities—are seen by those who do to be “homogenous,” all the same (Oliver & Fonash, in McDougall, 2006, p. 396). They are all just handicapped and nothing more. This homogeneity must be maintained at a cost not only to accuracy but also to the people whose identities are being re-inscribed, often in subtle, but damaging ways.

Many people suffering from chronic illnesses or disabilities are focused on as the subjects of research, but as people, they are rendered invisible. Too easily their narratives can become the stories of disease, rather than the stories of “the impact of an illness on a person’s life” (Sullivan, 1986, p. 332). In narrative studies, narratives are often treated as data for a researcher. They do not, however, come into existence as data, but instead as a process of identity formation that has profound significance for the narrator. They are formed as individual stories that are only generalizable to an extent. If they are generalized too far, they can dehumanize their subjects and turn them from people into cases.

Writers in a variety of disciplines have started questioning traditional Western knowledge structures and their impact on the individuals who are being researched (Davis, 1998; Denzin, 2005; Fontana & Frey, 2005; Kirmayer, 1992; Kleinman, 1988; Marks, 1999; Pratt, 1992; Sullivan, 1986). This has led to various types of resistance and subversion. Autoethnography is one of them.

Autoethnography as Writing About One’s Objectified Self

One way of resisting objectification by others is by writing about oneself. This type of research writing is sometimes known as autoethnography, but has also been known by other names, such as personal narrative, reflexive ethnography, complete-member research, experiential text, indigenous ethnography, and heuristic inquiry (Ellis & Bochner, 2000; Wall, 2006). Although this way of writing has been seen as inappropriately emotional, personal, or therapeutic, at the expense of

being academic (Atkinson, 1997), it allows researchers to show how they are part of a larger cultural context and to document the details of the lived experience of individual people (Ellis & Bochner, 2000). Sometimes these narratives show that individual experience does not fit theory (Ellis & Bochner, 2000; Muncey, 2005).

The very structure of this narrative mode of inquiry (Richardson & St. Pierre, 2005) creates a type of resistance to any notion of authorial omniscience and objectivity. Possibly for this reason alone, autoethnography is particularly suited to writing about illness and disability. After all, in the end, the lived experience of illness and disability is their reality and those who must live with this reality are those who live it, not those who study it from a distance. The voice that is heard most often in medical narratives of various sorts is the voice of the distant expert, and this voice can be quite pernicious. After my transplant, another doctor told me that the graft (as he called it) was taking nicely and that my results all looked good. Then he looked at me wistfully, with his head on one side, and asked, “What does it feel like to have had a transplant? Do you feel different from before? In what way?” I tried to explain it in sensory terms that I thought would fit into his medical point of view by explaining how much clearer my head felt and how much less tired I was. Food tasted different too. I could not explain how it felt emotionally, because it took some years before my feelings grew back, but that was the part of the story that was actually my own. That was what it was like to me.

Even now, all these years later, I am only able to discover the conflict I felt through writing about it. I was torn (and still am) between being humbled by my great good fortune at having my life saved (and being able to become well for the first time), and a disturbing sense of having to cope with a different type of identity damage to what the newly ill experience (instead of not knowing who I am as a newly ill person, I battle even now with not knowing who I am when I am well). I now wonder if I would belong more comfortably in a category for people who arguably are not well in the conventional sense and whose health comes at a price. Frank calls this category “remission society” (1995, p. 156), but I suspect transplantees need a society of their own.

I began writing my own story to do away with the subject/object divide, but I soon found writing about events in my past is not without its perils. On the one hand, writing about my 22-year-old self while many years older gives me distance, experience, and an

additional degree of perception (Csordas, 1997; Hertz, 2006). If nothing else, I know now that I got a kidney and that it works well, whereas back then I had to live with the very real possibility of dying without getting one. I have a type of closure that colors and shapes my narrative. On the other hand, I did not keep a diary of those years. I see myself then almost as another person. I wondered at first whether I would objectify myself even while I attempted to reconstruct my own past. If I discover many versions of myself, perhaps I can write about my reality in the present, which includes the past (Ellis & Bochner, 2000).

Had I not been ill for so long, I could have grown up being more carefree. I do not know. At my eighth birthday party, for instance, I might not have wondered during the egg and spoon race how soon I was going to die, instead of wondering whether or not I would win the race. I would not, 30 years later, still be haunted by my own vulnerability so that every fever or unexplained symptom takes on a dreadful significance of impending doom. Even now I do not know what being well is.

In addition to self-awareness, autoethnography can also be seen as developing “an awareness of the social, economic, and cultural processes that make up our lives” (Marks, 1999, p. 187), which is crucial in any study (particularly of identity or illness) that hopes to reconstitute identity (Jones, 2005; Richardson & St. Pierre, 2005). Reed-Danahay (1997) sees autoethnography, therefore, as a means of questioning the binary split between self and society and between subjective and objective. Her explanation of autoethnography is important because she gives both the “auto” and the “ethnography” parts of the term equal weight and describes them as challenging the idea of an objective, coherent identity in a world that no longer supports such beliefs. In terms of disability studies, this is not the only binary split that needs to be questioned. Another is that of disease as the medical understanding of the condition and illness as the embodied experience (Sullivan, 1986).

I could add a more difficult and debatable split: self and illness/disability. A story I only know from my mother and doctors, but cannot remember at all, has been indelibly etched on my life. At eight months I started having seizures and a raging fever. I was rushed to hospital where the doctors discovered I was suffering from massive internal bleeding. I was hemolyzing (my red blood cells were fragmenting). I burst a hole in my heart. My liver shut down. I did not pass urine for 12 days. Then I hemolyzed again. I survived. When I hear this story, I feel as if I am “the girl

who lived.” You cannot be the same after something like that. My illness is not the only thing that defines me, but there had been so little of me before it that I find it hard to escape a medicalized view of my life. That view comes to me largely through other people, which makes me wonder if it can really be called my story, although it is about me. And yet, identity—how I see myself—cannot be decontextualized (Bochner, 2001). That medical narrative is part of me, but to what extent?

Autoethnographic writing can help to provide a thick and textured description of a state of being and also to interrogate assumptions about that state of being (Ellis & Bochner, 2000; Ettore, 2005; Muncey, 2005). Autoethnography can address and problematize the role of the researcher when the researcher is explicitly located in a narrative and therefore cannot be understood as absent or neutral (Hertz, 2006). Warren et al. (2000) refer to this process as “the dialectic of revelation,” in which the writer and reader cocreate or (re)negotiate an understanding of a shared situation (p. 183). An autoethnographic study of the adult children of parents with psychosis illustrates this.

So, perhaps it is possible to be both self and other, it is possible to be both subject and object. I could be the adult child of a parent with psychosis—an insider, and a qualitative researcher—an outsider, and both of these roles afforded me opportunities as well as challenges that might not have been present if I were simply one or the other. (Foster et al., 2005, p. 6)

I look forward to being both the insider and outsider in my own story and seeing what this will show me. At any rate, I might be able to escape from a narrative I did not write. The imperative to conform to it has stopped me writing until now.

This is not all. Writing on one’s own illness or disability can do something else as well that is not always required in other types of autoethnography. Frank claims that when one tells one’s story, one is in fact repairing a damaged self and, rather more radically, that the self is not the cause of the narrative, but the product (Frank, 2000). Although Frank’s aim in writing, and writing about illness narratives, is “therapeutic and emancipatory” (2000, p. 136) and his view of representing the self seems at first glance to be similar to the ones I have been discussing, he has, in fact, different goals. He is less concerned with discovering or representing meaning communally than he is with creating a meaningful self.

If the teller is not completely “at home” in one world or the other (Reed-Danahay, 1997, p. 4), this

allows him or her to transcend everyday conceptions of self and society and, to some extent, to rewrite them. Through telling our stories, we make ourselves. We validate our new identities. We give meaning to our suffering. Our stories shape and structure our experiences rather than simply presenting them to a reader. They tell others who we are, but they also tell us. And more than this, they can make us who we are.

Autoethnographic Forms of Illness Narratives

Narratives that are written by people who have been in kidney failure or had a kidney transplant are few in number and difficult to find. They tend to be strongly in the form of a disruptive illness exorcized by a miraculous gift. The titles speak for themselves: *Transplant: A New Life After Kidney Failure—A Dramatic Personal Account* (Etherington, 1991); *Perfect Match: A Kidney Transplant Reveals the Ultimate Second Chance* (Hermans, 2006). There are far more self-help books involving the topic (Canfield & Hansen, 2003; Canfield, Hansen, & Reber, 2006; Johnson, 2007; Parr & Mize, 2001; Stein, Wild, Woodroffe, & Taylor, 2002). By and large these are written from the outsider's point of view: care providers, friends, and family. Since there are few first-person accounts of kidney failure, transplantation, and recovery, I have not been able to rely on narratives written by people who have experienced this, and have turned instead to other types of illness narrative to illustrate the points I make next.

Categorizing illness autoethnographies can be done in various ways. Ellis and Bochner (2000) place illness narratives in the bigger picture of autoethnography, whereas Kleinman, who coined the term "illness narratives" (1988, p. 28), does not describe them as autoethnographic; nor does Frank (1995), whose concerns are with the outcome of the narrative more than the narrative itself. Generally speaking, I see autoethnographic illness narrative falling into three main categories: testimony (Jones, 2005), emancipatory discourse connecting indigenous epistemologies (Denzin, 2005), and destabilized narrative (Frank, 2000). The boundaries of these categories do, of course, blur. All have been crucial in the areas of health psychology and disability studies and all have profound theoretical and philosophical implications for representation in the fields. Before analyzing these implications, it might profit us to explore what these three categories are.

Testimony

Testimony is the type of autoethnography that is most widely read and the kidney narratives I referred to earlier are this type of narrative. For the writer this allows a chance of being heard and understood. This type of autoethnography is the most autobiographical, detailing the struggles of an individual life. The context of the story is, however, still essential to understanding it.

This type of autoethnography allows people to put back together lives that have been dismembered and damaged and to make sense of them. In disability studies this is necessary to the identity and self-worth of the narrator and can help a person feel whole again. This extends beyond being therapeutic to the writer. Such narratives can also reveal a situation to readers who might be fellow sufferers, health care professionals, care providers, family, friends, or other interested parties. Testimony can give unique insight into experience, from people who have actually lived it. It can capture a depth of subjective experience that objective data cannot describe.

In short, it can allow both insiders and outsiders insights into what it is like being there. Lucy Grealy's *Autobiography of a Face* comes to mind here (Grealy, 1994). It tells the stories of two different illnesses: the first, that of an individual child affected by a rare cancer; the second, that of a culture obsessed with physical beauty. This type of autoethnography has a therapeutic dimension to it, where a damaged self is allowed to be expressed and "re-membered," or healed. There is another dimension to it, however, beyond therapy. Jones (2005) explains how autoethnographic narratives serve to disrupt, make agendas explicit, and to draw attention to "the power of the in-between" (p. 784).

Emancipatory Discourse

The second type of autoethnography, although still autobiographical, is more deeply imbued with context. Interestingly, kidney narratives do not seem to take this form, possibly because the writers want to see themselves as normally healthy after transplant and our illness is not as stigmatized as many others are. Emancipatory discourse, though tracing the vicissitudes of a single life, concerns itself with the place of that life in a certain environment and the impact of each on the other. Emancipatory discourse gives a voice to the voiceless and can allow people to say the unsayable.

Another reason kidney narratives might not take this form is because that could entail discussing ambivalence about the miraculous gift or confusion about the second chance at life. This could compromise the chances of people becoming organ donors, and it is uncomfortable to seem to be profiting from another's death. What if the truth about our anger, grief, and confusion alienated the doctors? We shall always need them to treat us.

Emancipatory discourse breaks silence. For people who are othered, this can be a powerful means of improving their position in society. It can allow them to be seen in a more complex way and to show that the group to which they belong is varied and complex—and frequently consists of many people. This type of autoethnography might go part of the way to help develop what Marks (1999) describes as a multifaceted understanding of disability, “which recognizes the importance of examining the interrelationship between embodied subjects and complex social and psychic relationships” (p. ix). Andrew Sparkes (1996), as a sportsman and sports science researcher with a severe back problem; Lennard Davis (1998), as a person with a severe hearing impairment and an academic with a passion for literature; and others have written about their contexts, using themselves as focalizers to allow their readers to concentrate on the effect of an environment on individuals and vice versa.

The Destabilized Narrative

The last type of illness autoethnography is the most complex and difficult to achieve, and can most clearly be seen in terms of destabilization (Frank, 2000). More often an autoethnographic narrative concerns itself with something that seems the same as destabilization, but is not: disruption. Disruption implies temporary perturbation which is subsequently normalized and smoothed over, as often in kidney stories. Destabilization means that the whole narrative changes and will never be the same again.

The most usual form of the disrupted narrative in disability studies is the narrative of “an individual life interrupted by illness” (Garro, 1992, p. 101). In the narrative, what usually happens is that a person is healthy, falls ill, and then either recovers, stays the same, deteriorates, or dies. The illness is constructed as a type of narrative disruption. Most often the disruption will somehow be healed. Recovery of the ill person is the most literal type of healing, but if this cannot be achieved, imbuing events with meaning will achieve narrative stabilization.

That people without illness or disabilities impose such patterns on narratives about people who are ill or disabled is well known (McDougall, 2006). What is not perhaps so well known is that the ill and disabled themselves often impose similar patterns acquired from the dominant ideology on their own narratives. Narrative forms in Western culture teach readers (and writers) to expect that a story will show an abstract and important meaning, such as courage under adversity, tragic waste of human potential, heroic triumph, or the making of a guru/saint/prophet. Though on the whole uplifting, these types of narrative tend to elide complexity and individuality, and can be as damaging as the negative versions (Davis, 2001). Somewhere along the line, the out-group person, who will be writing for those who are not out, will return to the in-group world, and his or her suffering will be imbued with meaning (Etherington, 1991; Hermans, 2006; Klug & Jackson, 2004). Reality is not always like this. I maintain that meaning(s) can be found, but, in a postmodern world, what is found might not be a Grand Universal Theory.

Grand universal theories can create closed, simplistic narratives. A charge against such narratives is that they exclude and “other” different voices in the narrative (and even sometimes the readers themselves), or attempt to assimilate other voices or the readers into the writer's identity. Less philosophically, these narratives can be a type of dead end and might not achieve any type of emancipation. They might even be charged with normalizing an othered life. Far from strengthening the position of people who are disabled or ill, these types of narratives might actually reinforce the very stereotypes that they try to undermine by representing them as desirable or undesirable all over again.

An alternative to this is a destabilized narrative (Frank, 2000). This is a narrative where different points of view are shown, but not assimilated into the authorial voice. This type of narrative is more open-ended and demands more from the reader. It does not do all of the thinking for the reader. Instead, it shows how messy and contingent reality can be. It shows the different points of view and different positionings in a given situation. It shies away from the myth of a single transcendent truth or closure and it shows the underlying theoretical assumptions that inform the positions being examined. This last function helps create a more politicized narrative (in a similar way to the argument Marks (1999) makes about the politics of disability raising awareness of oppression by others and by oneself), but it uses an intensely individual and subjective point of view to

achieve this. It is, in short, an attempt to use representation in a postmodern way.

Most importantly, it invites the reader to cocreate meaning and to discover what his or her own positioning is in a given context. This encourages resonance in the experiential world. Fadiman's (1997) *The Spirit Catches You and You Fall Down* is an example of such a narrative. It is constructed in such a way that allows readers to explore thoroughly their own assumptions about both Eastern and Western medicine and, in fact, to draw their own conclusions or change their minds. The narrator, although not ill herself, is highly othered and, therefore, highly visible. She acts as a doorway into the narrative, allowing the reader to grow along with her in her understanding of the complexity of the story of a Hmong child with epilepsy in the United States, and then to contemplate what that child's life could represent in the broader contexts of American medicine and Hmong culture. Each chapter is told from a different point of view (the doctors', the researcher's, the parents') and each is so persuasive that the reader keeps changing his or her mind until the very end. In addition to this, even though the reader is presented with a wealth of data, she or he is not given closure, but must continue to puzzle out the story of the child. The solution to the problems is not given in the end.

Such narratives can be the most effective types of autoethnography. They problematize representation and they challenge the idea that there can be one type of authority to which other subjectivities are subservient. When working with people it is important to be able to understand their point of view, but it is equally important to be able to understand one's own and to see how one might objectify others. Writers need to be aware of what they are doing when writing about other people.

Anatole Broyard's (1993) *Intoxicated by My Illness* achieves a similar result to Fadiman's (1997) narrative through virtue of being a posthumous collection of his writings on illness and death. The collection includes excerpts from his diary, essays, and a short story he wrote many years before about his father's death from the same disease that would eventually kill him. The story is included at the end of the collection and is one of the ways in which the larger illness narrative of Broyard's anthology is destabilized. In the context of the anthology, the short story shows the reader two things: There are many Anatole Broyards, some of them being Broyard then and now, Broyard ill and well, Broyard mourning his father and himself, Broyard as patient (object), and Broyard as

critic (subject). It also shows the reader what one would have seen if one could have followed Broyard to the very end, after he became too ill to write. Although horrifying, it serves as a reminder that observers can only ever be outsiders. When we close the book, our story continues; Broyard's does not.

Autoethnography as Destabilizing Practice: Writing the Self or Wronging the Self?

Autoethnography can be seen as a form of emancipatory discourse because those being emancipated are representing themselves, instead of being colonized by others and subjected to their agendas or relegated to the role of second-class citizens. However, in representing themselves, those writing about themselves could replicate the very structures they seek to destroy, reverting to inauthentic identities that others have bequeathed them (Marks, 1999).

Writing about oneself presents certain unique problems to the writer. Who am I writing about when I write about myself? Am I writing about myself here and now, or there and then? Is the me of yesterday the same as the me of today? If not, then I run the risk of objectifying a version of myself all over again.

Often the aim of such writing is to win back some power to a certain group of people, but it can be seen as distracting attention from the bigger issues (Marks, 1999, p. 183), and might result in self-subjection, voyeurism, and pathologism. It might reduce the narrator to a generalizable case file example, instead of bringing about change. If it is too individualizing it might create a dualism of individual/culture (Reed-Danahay, 1997). This could lead to the individual being seen out of context and the dynamic of the individual and society being overlooked.

Although autoethnography can allow people to define themselves (instead of being repositories for other people's ideas) and reveal the processes that create disability as a concept (Marks, 1999), Kleinman (1992) points out that this might not prevent one from reproducing the processes one is trying to dismantle. However, Reed-Danahay (1997) shows that this type of reproduction, instead of being a type of collusion, might be a mode of resistance, such as collaboration (in which a new reality is formed) or appropriation. When the discourse of power is in the hands of the underdog, the power distribution shifts, even if only briefly.

Self-subjection is diversionary and voyeuristic and therefore does not bring about change. It can be avoided if one's work is theorized and politicized and yet remains individual (Garro, 1992; Kleinman, 1992) and specific, not abstract (Marks, 1999). Marks (1999) points out that the political is embodied in the personal, and vice versa. Autoethnography can help readers to remember this by problematizing this relationship.

One of the biggest challenges in writing about illness is how to portray experience without reifying it or simplifying it (Miller & Crabtree, 2005). Writing about illness poses particular problems—or, perhaps, highlights particularly the problems of writing about human experience. The meaning of impairment should perhaps be what it means to an individual experiencing it: the meanings of impairment in a given life.

The context of that life will reveal similarities and differences for the readers (Marks, 1999). At the end of the narrative(s) a single, coherent identity might not emerge. The identity might remain contingent (Marks, 1999), even fractured. This is not necessarily a problem and relates to Frank's conception of destabilization (instead of disruption) of a narrative (Frank, 2000). It also relates to postmodern views on representation. Postmodern autobiography questions the "notion of the coherent, individual self," whereas postmodern ethnography questions "the realist conventions and objective observer position" of standard ethnography (Reed-Danahay, 1997, p. 2). Autoethnography combines these approaches and allows the narrator to be both subject and object, but not to escape being either. It can allow a writer to keep the tension between these states, which is a central aspect of identity for a person who experiences disability or illness.

Perhaps autoethnography moves beyond questioning these splits and becomes a means of bridging the divide. Reed-Danahay sees autoethnography as a way of enjoying a "dual consciousness" and allowing "boundary crossing" (1997, p. 4). Jones (2005) elaborates, explaining that autoethnographic narratives resist categorization and closure. Jones also notes the liminal nature of autoethnographic writing, describing it as being "between story and context, writer and reader, crisis and denouement" (2005, p. 764). She points to "the power of the in-between," of occupying a space between theory and practice, analysis, and action (2005, p. 784). From the perspective of a mind that wishes to have answers or control, this could seem inconclusive.

My view is that experience retains its power (but also its control) when it retains something of its enigma or

mystery. I do not, however, believe that this is a solution. Instead, I think that subject-object dualism is dynamic and that each part feeds into and learns from the other. Perhaps subject-object dualism is more effective if it is not collapsed, but rather allowed to permute and develop, both sides seen as interdependent parts. Insider research is a way of achieving this. I can be both transplant recipient and researcher. I can have the experience and write about it. I can research its meaning so that it is meaningful to others, too, and so that its context is illuminating. If this were true, it would be closer to what Descartes (1984) originally meant by the mind and body playing different roles. Instead of trying to do away with the perceived problem of subject-object dualism, one could allow it to play itself out—for both parts to talk to each other, never allowing either side to become dominant.

In the course of my research so far I have read "quite a bit," but at present there is one line that stands out in my memory. Ellis and Bochner's chapter on autoethnography (2000) contains a detailed introduction to the method, as well as the story of a woman, Sylvia, who had cancer, starting to write about her experience several years into remission. She said, "Now I realize I don't have to pretend" (Ellis & Bochner, 2000, p. 756). She realized that she did not fit into the narrative of the happily-ever-after survivor story. When she accepted that her reality was more complex, she could write her own narrative at last. It would have meaning for her and others. Relatively little personal writing has been done on kidney failure and transplantation. A possible reason for this is that we, too, are meant to fit into a happily-ever-after narrative we did not write. My reality is more complex. For one thing, my dysfunctional family did not fit the kidney transplant script of being united in the fight to save my life, and unanimously supportive of my struggle to survive.

My kidney is functioning brilliantly, even after 16 years, and I have been healthy so long that I can afford to feel regret for what I never had growing up (for instance, that feeling of immortality that young people are supposed to enjoy). Sometimes now, at last, I wonder how different my life might have been had I not had hemolytic uremic syndrome. I work at a university and am surrounded by students who are the age I was when I was most ill. I see every day how different their lives are from mine at that age. I also realize that my medical condition and I are so closely entwined that we probably cannot be separated. We have been together all my life and always will be, because, although I am well, my health comes at a

price that is both financial and medical. My medication costs money and has side effects. I need to be treated by a specialist. My condition, the aftermath of a dreaded disease, is not covered by all forms of insurance. I shall always have to attend clinics and avoid certain things (alcohol, direct sunlight, contact sport, having children). My health can be taken away at any minute.

In Conclusion

Writing and, indeed, reading are not unproblematic acts. Traditionally, academia has attempted to render these processes as transparent as possible by establishing certain rules that were intended to make publicly shareable the writing and reading of research. Autoethnography attempts to challenge the beliefs behind these rules. It does not, however, simply demolish. It seeks also to rebuild. It does not seek to replace, but to provide alternatives and to show that certain types of information can be gained from using autoethnographic methods and that this information cannot be gained from using traditional methods. It makes apparent the experiences of being writer and reader, by problematizing the processes of writing and reading. "The politics and poetics of representation" (Reed-Danahay, 1997, p. 3) go part of the way to describing these processes and experiences.

Combining autoethnographic narrative with more conventional research allows research into illness and disability to reach two distinct audiences: the health care professionals (researchers, doctors, nurses, and counselors) and the lay people (patients, families of patients, carers, and friends). A narrative approach with a strong theoretical and ethical grounding could allow the professional care providers access to the lived experience of illness, rather than just the data and symptoms. In addition it could allow people from the broader chronic illness community to see some of their experiences reflected. A destabilized narrative might empower both groups to question their beliefs and attitudes to illness and disease and thereby come to new negotiated understandings of their positions. This could impact the treatment of patients and the ways in which people manage their own conditions. It could also help all those involved in illness and disability studies to be heard, not only as functions (professionals or patients), but also as people whose lives and work are often difficult and who all need compassion (Foster et al., 2005).

The lived experience of illness and disability is perhaps their ultimate truth and is a truth that can seem inaccessible to outsiders. This should not, however, prevent researchers from attempting to reach it. New approaches to studying the experience of illness and disability can open up new questions which are sometimes more useful than answers.

It is nearing the end of the consultation. I am reminded that my history is inscribed on and in my body when my new urologist shows me my kidneys on the sonar. The big, healthy, new one is in my pelvic girdle, where kidneys never grow naturally. He would not know to look there if I had not told him about my transplant, because my other readings are so normal. But, although the little, old ones are in the usual place, they are harder to find. When I last saw them 16 years ago on my posttransplant scan, I was shocked to see how small and shriveled they were, no more than 8 cm long. They are even smaller now, 6 cm from what we can see, and calcified. I swallow a lump in my throat. "They did their best under the circumstances," I tell my urologist.

He nods. He knows what I mean. We look at them together in silence for a while. Then I start to realize that my body shows only part of my story—some of the details of my past—but it does not show their meaning. I shall have to do that, and I am still becoming myself.

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