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"YOU LOOK VERY WELL FOR A TRANSPLANT" : AUTOETHNOGRAPHIC NARRATIVE AND IDENTITY IN CHRONIC KIDNEY DISEASE, KIDNEY FAILURE AND THE LIFE POST-TRANSPLANT

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THESIS

ENGLISH ABSTRACT: Despite the high prevalence of chronic kidney disease, renal narratives are under-reported. Much of what is written on kidney failure is written by health care professionals for health care professionals and about patients. While medical experts and health care practitioners have one type of knowledge, their patients have another type of knowledge acquired through their experience of their own condition. From within the disability and patients' rights movements urgent calls have been made for the authentic voices of disabled people and patients to be heard without the mediation of professional lenses. In response to this my dissertation combines personal and academic writing to explore my own experience of end-stage renal disease, dialysis, transplantation and the life after transplant. I have used autoethnography as a methodology. Autoethnography is a relatively new, somewhat postmodern form of inquiry that developed from the reflexive turn in anthropology and narrative studies in the latter part of the twentieth century. It is very useful in writing about the experience of illness and reflecting on illness narratives because, in autoethnographic writing, the observer and observed, the narrator and narrated, insider and outsider are the same person. This allows scope for exploring the problematics of representation and for finding alternatives to already existing ways of telling certain stories. Engaging with autoethnography's postmodern aspects has allowed me to conceptualize experiences that, until I undertook this research, I have never been able to articulate, because the traditional (static) illness narrative forms did not speak to my experience or my understanding of my condition. The central issue in my dissertation lies in the question: How do I tell the story of chronic illness once I have had an organ transplant? Flowing from this are a number of sub-issues: Can my story change? How do I describe myself: The well, the ill, the impaired, the disabled, the afflicted? Do I describe myself living in no man's land? In my narrative, do I oscillate between being well and ill, or do I occupy another territory entirely? And if I do, what is it? My study shows that writing the story (or stories) of chronic kidney disease is complex, nuanced and dynamic and that, far from being an extended liminal experience, kidney disease is littoral. This distinction is important in coming to narrative terms with an identity that is not damaged so much as different. Through this I hope to demonstrate to both outsiders and insiders, who often submit to narratives that are forced on them, that more satisfying alternatives can be found.

AFRIKAANSE OPSOMMING: Ondanks die hoë voorkomssyfer van chroniese nierkwale word nierverhale nie genoeg aangemeld nie. Die meerderheid van dit wat oor nierversaking geskryf word, word deur gesondheidsorgdeskundiges vir gesondheidsorgdeskundiges en oor pasiënte geskryf. Terwyl mediese deskundiges en gesondheidsorgpraktisyns een soort kennis het, het hulle pasiënte 'n ander soort kennis op grond van hulle ervaring van hulle eie toestande. Van binne die gestremde en pasiënteregte-bewegings het 'n dringende oproep weerklank vir die outentieke stemme van mense met gestremdhede en pasiënte om gehoor te word sonder die tussenkoms van professionele perspektiewe. In reaksie hierop kombineer my verhandeling persoonlike en akademiese beskrywings om my eie ervaring van eindstadium- nierkwale, dialise, oorplanting en die lewe na oorplanting te verken. Ek het outo-etnografie as metodologie gebruik. Outo-etnografie is 'n relatief nuwe, ietwat postmoderne vorm van ondersoek wat in die tweede deel van die twintigste eeu uit die refleksiewe wending in antropologie en narratiewe studies ontwikkel het. Dit is baie bruikbaar wanneer oor die belewenis van siekte en besinning oor siekte-narratiewe geskryf word aangesien die waarnemer en die waargeneemde, die verteller en dit wat vertel word, die ingewyde en die buitestander in outo-etnografiese skryfwerk dieselfde persoon is. Dit laat meer ruimte vir verkenning van die problematiek van voorstelling en vir die opspoor van alternatiewe vir reeds bestaande wyses om sekere stories te vertel. My bemoeiens met postmoderne aspekte van outo-etnografie het dit vir my moontlik gemaak om ervaringe wat ek tot en met hierdie navorsing nooit kon artikuleer nie, te konseptualiseer, aangesien die tradisionele (statiese) vorme van siekte-narratiewe nie tot my ervaring of my begrip van my toestand gespreek het nie. 'Hoe vertel ek die storie van chroniese siekte nadat ek 'n orgaanoorplanting gehad het?' is 'n sentrale vraagstuk in my verhandeling. Hieruit spruit 'n aantal newevraagstukke voort: Kan my storie verander? Hoe beskryf ek myself: Die gesonde persoon, die sieke, die verswakke, die gestremde, die aangetaste? Hoe beskryf ek myself wat in 'n niemandsland woon? Fluktueer ek in my narratief tussen gesond wees en siek wees of betrek ek 'n geheel ander gebied? En indien wel, wat is dit? My studie toon dat, om die storie (of stories) van chroniese niersiekte te skryf, kompleks, genuanseerd en dinamies is en dat niersiekte glad nie 'n uitgebreide liminale ervaring is nie, maar eerder littoraal is. Dit is belangrik wanneer daar tot 'n narratiewe verstandhouding gekom moet word met 'n identiteit wat nie soseer beskadig is nie, maar eerder anders. Hierdeur hoop ek om aan beide buitestanders en ingewydes, wat dikwels voor narratiewe wat op hulle afgedwing word, moet buig, te wys dat daar meer bevredigende alternatiewe gekry kan word.

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