
A thesis presented in partial fulfilment of the requirements for the degree of Master of Science

At
Massey University, Albany
New Zealand

Dany Yeats
2013
In New Zealand the prevalence of stroke in children is extremely rare. Medical specialists and health care practitioners possess a knowledge, whilst their patients possess a specific knowledge acquired over the course of their illness. The patient’s voice needs to be heard without the arbitration of a medical discourse. It is essential that a discursive space is found for the vocalization of the stories bound up within the statistics, facts and figures of the medical narrative. But how? I respond to this by blending our personal stories with academic writing in order to explore an adolescent’s experience of stroke, and our lives which have been interrupted by chronic illness, and disability.

I adopt collaborative autoethnography as a methodology for this research. Collaborative autoethnography offers a valuable vehicle when writing about illness as it allows for the creation of multiple spaces. As the researcher, I am the observed and observer, the narrator and narrated, I am an insider as well as an outsider, I am both believer and non-believer, doubted and doubter. I am able to occupy these and inbetween spaces. This diversity affords me the opportunity to create a discursive space to explore the problematics of representation. I am also able to develop alternative ways of storytelling so that I may capture the deeply complex, nuanced and dynamic experiences of chronic illness and disability.

As a feminist engaging with autoethnography’s somewhat postmodernist flavour I have finally been able to tell my story and conceptualise my experiences. Previously I had been unable to articulate my story as I did not truly understand my story due to traditional medical knowledge not allowing a space for placing it authentically within my understanding. This research tackles how the researcher mother can capture both hers and her son’s story, whilst also reflexively revealing the experiences of chronic illness and disability. Furthermore, can this type of research be undertaken ethically? Where does my story end and his begin? How do I voice my son’s story? Is he the hero, the survivor, the disabled, the victim, the triumphant, or other? How am I positioned as the woman, the mother, and the chronically ill patient? Are we well or are we afflicted, and which spaces do we occupy? If we oscillate between the two how do I describe where we reside? Do we stay in the frightening no-man’s land or do we move between spaces with an acceptance that there are no absolutes or certainties? And if so, is this not dissimilar to the life journey that all people travel? This research tackles an array of questions; however it is also aimed at raising
consciousness that within the state of chronic illness and disability alternative voices and spaces can be found. Moreover, these stories serve as both an academic tool and as a political protest performance by challenging conventional thinking and the medical paradigm which appears at times, paralysed.

This work illustrates that although writing stories about chronic illness and disability is deeply nuanced and complex, viewing chronic illness and disability as a fluid concept not bound within a Cartesian dualism of socially constructed norms of illness and health, and normal and abnormal is crucial. This notion proposes an extension beyond traditional binary epistemologies, and suggests a perviousness between bodies, an interconnectedness of other, both within and with other. This idea includes the essential relationship between the embodied subject and their world, and that an individual may hold dual citizenship as they develop in the world with others.
FORWARD AND ACKNOWLEDGMENTS

‘Without language, one cannot talk to people and understand them; one cannot share their hopes and aspirations, grasp their history, appreciate their poetry, or savor their songs.’ – (Nelson, 1994)

Many thanks to my Supervisor, Professor Kerry Chamberlain, who encouraged and supported me.

I dedicate this work to my son, James, with all my love.
Table of Contents


OF LIVED EXPERIENCES ........................................................................................................... II

ABSTRACT .................................................................................................................................... II

FORWARD AND ACKNOWLEDGMENTS .................................................................................. IV

CHAPTER ONE ............................................................................................................................. 1
  INVICTUS ..................................................................................................................................... 1
  INTRODUCTION .......................................................................................................................... 2
    Background ............................................................................................................................... 2
    About the Writing ..................................................................................................................... 3
    On being a NHI: An Illness Number ...................................................................................... 6
    Central issues captured in the writing of this thesis ............................................................... 7
    Reflexivity ................................................................................................................................. 7
    Awareness of the medicalised vulnerable self ....................................................................... 9
    The need for insider’s voices and disrupting the biomedical gaze ......................................... 10
    Explanation of thesis structure ............................................................................................. 11
    Structure of Chapters ............................................................................................................. 11

CHAPTER TWO .......................................................................................................................... 14
  THEORETICAL THOUGHTS ....................................................................................................... 14
    On finding a woman’s voice .................................................................................................. 14
    Methodological journey ....................................................................................................... 18
    Arrival at autoethnography ................................................................................................. 20
    Academic encounters ........................................................................................................... 23
    Autoethnographic review .................................................................................................... 25
    Insider, outsider, or somewhere inbetween ......................................................................... 26

CHAPTER THREE ....................................................................................................................... 31
  ETHICS ....................................................................................................................................... 31
    Introduction ............................................................................................................................. 31
    From ‘principlism’ to ethical care ......................................................................................... 32
    Autonomy, nonmaleficence, beneficence .............................................................................. 33
    Whose story is this? ............................................................................................................. 37

CHAPTER FOUR ......................................................................................................................... 42
  PATIENTS, POSITIONS, PERFORMANCE, AND POWER ............................................................ 42
    Introduction ............................................................................................................................. 42
    Patients and positions ........................................................................................................... 43
    Power and performance ....................................................................................................... 44
    Stories from under the biomedical gaze .............................................................................. 46
Struck down .............................................................................................................................................. 47

CHAPTER FIVE ............................................................................................................................................. 49
JAMES’ STORIES .......................................................................................................................................... 49
The battle for James .......................................................................................................................... 49
Adolescence and the abject body ........................................................................................................... 50
Sensemaking from within the liminal space .................................................................................................. 52
James within the liminal .................................................................................................................... 54
The road to recovery: Insights into James’ journey to health ................................................................. 57
The body as a social construct: The body as social judgment ............................................................... 58
The body as object: The body as subject .................................................................................................... 61
Repositioning the body through performance ........................................................................................... 62
Coping through immersion in peer group culture ................................................................................... 65
Conclusion .................................................................................................................................................. 67
One last story ............................................................................................................................................. 68

CHAPTER SIX ............................................................................................................................................ 69
CONCLUSION ............................................................................................................................................... 69
Experiencing Collaborative Autoethnography .......................................................................................... 69
Was it truly autoethnographic? ................................................................................................................. 71
What is the contribution? ............................................................................................................................ 72
What of aesthetics? ..................................................................................................................................... 73
Was it reflexive? .......................................................................................................................................... 74
Did it impact? .............................................................................................................................................. 76
Does it reveal lived experiences? ................................................................................................................ 76
Future research ............................................................................................................................................ 76
A last word .................................................................................................................................................. 77

REFERENCES .............................................................................................................................................. 78