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**Lives Interrupted – An Adolescent’s Experience of
Stroke: A [De]Construction and Reconstruction
Of Lived Experiences**

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

At

Massey University, Albany

New Zealand

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2013

ABSTRACT

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.

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CHAPTER ONE

INVICTUS

By: William Earnest Henley

Out of the night that covers me
Black as the Pit from pole to pole
I thank whatever gods may be
For my unconquerable soul.
In the fell clutch of circumstance
I have not winced nor cried aloud
Under the bludgeoning of chance
My head is bloody, but unbowed.
Beyond this place of wrath and tears
Looms but the horror of the shade
And yet the menace of the years
Finds, and shall find me, unafraid.
It matters not how strait the gate
How charged with punishments the scroll
I am the master of my fate
I am the captain of my soul.

INTRODUCTION

Background

The Beginning: 29th December 1994

I met him on his birthday. I was a relatively young mother, and it had been an unplanned pregnancy. Maybe he knew of my trepidations, as my son came into this world easily with little mess, no fuss, nor fanfare. He stamped his cool, calm, and collected style from the beginning. Up until then I had only known a careful love, but through an evolutionary tug I fell into complete love.

June 2009

This story began fourteen years later, on a Tuesday in June. It was a normal day, like so many before, my son came home from school. But on this day, he had been involved in a school yard fight. This was out of the ordinary, but on the other hand trying to parent a teenager my thoughts were maybe this is what happens, just roll with it. However, this fight would turn out to be so much more.

He did not look well, so later that evening I decided to take him to the local Accident and Emergency rooms for a check- up. He was given the thumbs up. It was determined that he may have a slight concussion and I was just to keep an eye on him. During the night, however, the symptoms worsened with nausea and severe headaches. It would be the next day before the full horror of his injuries would become known.

James insisted on going to school the next day. I allowed him to go in for lunch break then straight home again. After dropping him off he walked into school, pale, but seemingly okay. I drove away believing I would be bringing him home in an hour to completely recover, and then back to school later in the week. I was sure our lives would resume as normal. My cell phone rang 15 minutes later. It was the school nurse.' Please come quickly the ambulance is on the way, your son has collapsed'.

James is now eighteen years old. At the age of fourteen, on the 18th June 2009, he suffered a significant stroke (LMCA infarct sec LICA dissection (trauma) – NIH Stroke scale score of 16 (severe)) at school during lunch break. James' carotid artery had spilt after he was punched in the neck the day before.

Stroke is commonly viewed as an old age occurrence and is accepted as a manifestation of a general advancement of years; a component of the body's aging process. Within Western culture this slow deterioration of the body into old age is a recognised and accepted one. Although stroke is traumatic and distressing at any age, it can be viewed as simply part of one's ageing process. A journey towards an ending. Strokes are usually explained as being related to lifestyle factors such as, effects of smoking, excessive alcohol, stress and life style choices. These accepted ideas, in addition to an understanding and general knowledge regarding stroke, can serve to 'soften the blow' if one suffers a stroke in later life. However, when a previously healthy and fully functioning teenager suffers a stroke there are significant differences in attitudes and far reaching implications on biography, for it is a life still in its beginning.

There is much research and literature devoted to the physicality of stroke, however little has been published on the subjective meanings of the experience. We know what stroke looks like, but not how it feels. This research attempts to offer something useful out of a traumatic family event.

I am confronted by a multitude of questions as I delve into my research. One of the questions raised in this research is that of how this particular story can be told. How do I as both the mother and the researcher present an academic piece of work about my son, my participant, and his experience of stroke? To address this issue the research methodology I utilise is collaborative autoethnography. This methodological approach allows me to narrate my own experiences, and for the listener to hear my son telling a story of suffering a stroke at the age of fourteen. Our stories will be carried out against a background of illness narratives in general. I will use my story to contextualise James' and, to some extent, raise discourse between this narrative and others (Frank, 2010). Whilst collaborative autoethnography is central to my thesis, it needs to be seen in the context of other types of illness narratives, and this work will surely converse with these narratives as it progresses (Richards, 2012).

About the Writing

Throughout the thesis I change the authorial voice in order to examine, (de)construct, and reconstruct the deeply complex stories of chronic illness, rehabilitation, and coming to an acceptance of a life that has irrevocably changed. In alignment with the epistemological aims of autoethnography I have embraced a more personal style of writing, and thus avoided favouring the academic episteme over the subjective (Jones, 2005; Richards, 2012). I began this work with a personal story about my son James, and I conclude with him. These pieces

of narrative not only form part of the pieces of the puzzle which are essential for my understanding of my research journey, but by positioning James in the beginning and the end gives him the opening and closing statements. The first and last words, the autonomy, power, and control has always been his, and always will be.

The writing style does not follow conventional academic practice. It is a dodgy thesis. It is dodgy as the researcher is the mother of the participant child. I have played with a traditional structure of a thesis by blending qualitative health research and narratives. I express academic and personal, objective and subjective issues. I position myself as both doubt and doubter in order to depict, describe, and embody as accurately as I can a phenomenological research project about the experience of lives interrupted by chronic illness.

In a postmodern world stories unleash and give power to previously silenced and diminished voices. Writing from a feminist perspective is a means to knowledge production; a creation of a counter-knowledge which may challenge accepted and long held legitimised foundational knowledge, to arrive at an alternative but still a valid and valuable knowledge. However personal experience is not enough to claim a 'self-authenticated knowledge'. Authenticity is attained through writing with an understanding that experiences are already an interpretation which requires further interpretation (Jones, 2005). Thus the process of writing is a dynamic and evolving interpretation, and these unfolding and unveiling postmodernist performances form part of the storytelling (Jones, 2005).

Each experience of illness is unique (Hahn, 1995). Thus it can be proposed that each experience of becoming well is unique too. Regardless of how this story is framed within academic and theoretical contexts, our story of our experience of ill health, journeying to recovery, and subsequent 'wellness' is ours alone. Consequently, writing about our story is not to provide a generalisable outline, rather it is an attempt to develop deeper understanding, and to advance meanings for lives which are interrupted by chronic illness and disability. Through a storied account I am able to depict thick descriptions and multiple interpretations of the varying complexities of suffering with illness. It is here that recounting subjective experiences bypasses the common linguistic and often statistical accounts of experiences of illness, thus giving voice to previously silenced voices (Allen & Piercy, 2005; Jones, 2005). However, in enabling voices to be heard and stories to be told, representations are made and identities are proclaimed. Narratives may create shifts in representations which may, in turn, create shifts in identities (Allen & Piercy, 2005; Becker, 1997; Carter, 2002; Jones, 2005). I

write about these shifts, and I examine the discursive spaces that are shaped for, and by, the chronically ill and disabled.

The writing will also show that I am intimately and personally connected to chronic illness as I have been chronically ill for most of my adult life as well as being the mother of a chronically ill and disabled child. I use my stories in this work in order to contextualise James' story. However, in doing so, further questions are revealed. Are our stories connected? Do our stories change? Are we 'the well' or 'the disabled', 'the healthy' or 'the impaired'? Are we able to create and occupy new domains? If so, which spaces do we occupy? And what do those spaces look like (Dwyer & Buckle, 2009; Richards, 2012)?

A further issue I need to consider whilst writing is whether this research runs a predictable illness narrative pattern (Brody, 2003; Richards, 2008). Richards (2008) articulates that illness narratives may also contain patterns of abstract meanings, for example, 'heroic triumph' or 'courage under adversity'. Predictability has the potential of positioning illness narratives into a space of normalcy. Downgrading and simplifying the experience of chronic illness and disability into workable and generalisable findings enables illness narratives to be disambiguated so that they fit within acceptable frameworks for others to understand. This is in contrast to the multiple complexities and contradictions which embody illness (Couser, 1997).

Through my research I have been confronted with the mediation of other voices in illness narratives, in particular, an abled bodied academic mediating the voices of their ill participants. I do not wish mine or James' voice to be mediated, nor do I wish to mediate another's. Therefore, an aim of my writing is to avoid the problems of assumption that so often misrepresent and weaken collaborations between nondisabled researchers and 'their' disabled participants (K & Duncan, 2006).

Consequently writing within a collaborative autoethnographic methodology allows me to problematise my research. It enables me to turn to other illness narratives to help support, dispute, and shape my articulations. It supports the means and voice to unravel and untwist, to blend and blur different theories, hypotheses, and thinking. I am able to examine, explore, and challenge different paradigms in order to offer a counter discourse and to arrive at diverse meanings. Given this, I am afforded the opportunity to propose a more satisfactory knowledge and thereby help to ensure against personal literature on chronic illness being vulnerable to general dismissal (Couser, 1997). This story is framed within the context of other illness narratives and within the medical context. Its primary concern is the subjective

experience of chronic illness and disability. However, the writing is also intended as a form of advocacy, and a raising of awareness in order to disrupt long held Western beliefs and ideas regarding the 'unwell'.

On being a NHI: An Illness Number

'At its most arid, modern medicine lacks a metric for existential qualities such as the inner hurt, despair, hope, grief, and moral pain that frequently accompany, and often indeed constitute, the illnesses from which people suffer' (Greenhalgh & Hurwitz, 1999, p. 50).

Leder (1990) explains how a patient is stripped of their identity and agency within the dominant medical discourse. They are required to assume a motionless, resigned, mute, and subservient position whilst a mechanist technology is practiced in an attempt to return the patient to normal. I have included excerpts taken from James' medical notes in order to offer the Reader some insights into the severity of his stroke. I also wish to showcase the discourses of rationality and logic inherent within the medical discourse, in addition to the lack of emphasis on the individual and agency. Likewise, these dialogues tend toward the construction of dualistic modelling such as mind-body, illness-wellness, normal-abnormal, and subject-object (Kierans & Maynooth, 2001). These issues are explored further within this research.

'James is a previously very fit and well 14 year old young man. On arrival in the Children's Emergency Department James was severely dysphasic, displaying severe lower right facial weakness and full gaze. He was hypertonic with significant clonus and pathological reflexes. James was commenced on an anticoagulation initially with heparin and subsequently warfarin. He was commenced on nasogastric nutrition because of his lack of facial movements and difficulty with oropharyngeal motor control. James will require long term anticoagulation because of his internal carotid artery dissection. This will reduce, but unfortunately cannot entirely eliminate the risk of subsequent stroke. He is also at risk of subsequent Moya Moya and if this is to occur it is more likely to be within the next couple of years. Because of his area of infarction James is at risk for seizure disorder. If James is to suffer from seizures as a result of this stroke these are likely to occur within the first six months. James has had a child disability allowance application form completed. James will receive intensive

outpatient rehabilitation from the Wilson's Centre. He will be reviewed for visual field testing and ophthalmology review because of a concern regarding alteration in peripheral vision. James is unlikely to be able to return to full time education for some months. This will be done in close consultation and guidance from the Rehabilitation team at Wilson's Centre.'

Central issues captured in the writing of this thesis

A focus of my research concerns the problematics of writing about my own experiences of chronic illness whilst narrating James' experience of stroke; his struggle with rehabilitation, and life afterwards. This is further compounded by the observer and observed, the teller and listener being the same person. Complex challenges of voices and authenticity in the unfolding processes, performances, and production of this study are raised. I am confronted with issues of unravelling subjectivism and objectivism, and other issues of representation (Riessman, 1993). However, through the processes of reflexivity, critical analysis, and with the autoethnographic method promoting interpretive characteristics I am given the means of examining and questioning these assumptions. I have become aware through the processes of my research that without my experiences of chronic illness, and my insider perspective, I would never have been able to tackle this subject matter as a research project. My personal experiences enables me insight and understanding into matters that are generally screened from others. It allows me to not only create context by telling my stories, but I am also able to reveal the very inside of our stories - the messy, the deeply nuanced, complicated and contradictory, and at times the unthinkable. I possess the specific knowledge, the feelings, and the understanding that goes beyond mere recounting of experience.

Reflexivity

'Everyone ... holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.'
(Sontag, 1978).

I am what Sontag (1978) identifies as a 'dual citizen'. However, as I write I also move between the realms of academia and into the space of researcher, and then I move

again, and hover between the domains of the ill and well in order to tell our stories. I am aware that I move continually. I oscillate between, and occupy many spaces.

My part of this story began twenty years ago; however, twenty years ago I did not have the voice to articulate my story. I have been told that there always comes a time when it is right to tell a story, unfortunately my time came when my son had his stroke. It was this awful incident that opened a floodgate of telling. What changed? Why now? Perhaps watching my son suffer, him clinging to life, and reclaiming what he knew was rightly his enabled me the courage to look inside. Perhaps time, age, and experience allowed a more mature me to find my space and access points of reference to be able to articulate parts of this story.

20 June 2009

James' bed is up against the wall next to the big window. It is the second day of his hospitalisation. He has right side hemiplegia, but today he has begun to stir, to move and moan. Throughout the day his movements increase. I am exhausted and have sat vigil for forty eight hours. It seems as if it happens very quickly. He is up. He pulls the right side of his body as if he is burdened by a heavy load. I watch. Left foot off the bed, and then he pulls the right side of his body to catch up. He is going for the window. I watch. His unfocused staring eyes have become concentrated, and shine with purpose and determination. He is going out the window. He is pushing the top half of his body through the small opening. I watch. Standing up I help support him. I do not try and pull him back but let him know he has succeeded. He has got out of the bed and he is telling us he wants out – and I am listening.

June 1997

Click, Clack, Click, Clack. The TPN unit I am hooked up to makes this noise – it has gone on for over six weeks. I am in the ICU unit in a hospital in Cape Town. Click, Clack, Click, Clack. I have tried telling the doctors and nurses that something is very wrong with me. They do not listen. I am feeling worse and worse. They do not listen. Please God, my prayer has changed from let me live to please let me go. I want out. And I do get out. I do not have a window to go to; instead I have a grand mal seizure. Exquisite release. I wake up. Now they are listening. The epidural I have had to block the pain from the emergency surgery to remove my septic, and ruptured colon has been leaking spinal fluid for days. Drip, drip, drip.

I wanted to pursue these stories within my master's research as I need to provide myself with an academic framework and context against which I could consider our narratives. Within this, reflexive practice is core to this work and underpins the very fabric of the storytelling. Parker (2005) explains reflexivity as not simply a set of academic tools but rather a subjective way of knowing and being in the world. Moreover, my understanding of reflexivity includes a critical self-awareness regarding the formulation, structure, and construction of this research. I am therefore able to embrace both my own and James' lived experiences whilst occupying multiple spaces. Practicing reflexivity also allows me to offer not just a subjective opinion and description of the process of chronic illness, but I am also able to narrate aspects of the conceptual and active processes undertaken in producing an academic piece of research. On another level I remain constantly aware of the reciprocal influences between myself, the mother, the researcher, and my son. Further I am guided through deep self-introspection to better understand myself and others (Anderson, 2006).

Through reflexive practice I have come to know that I would not be able to undertake this research without deep self-reflection, scrutiny, awareness, and critical analysis. This includes a constant (re)examining of my epistemological standpoint, and confidence in my methodology.

Awareness of the medicalised vulnerable self

Western culture inclines towards constructing illness and disability in ways that are alienating and disabling (Couser, 1997; Sontag, 1978). Despite the unsurpassed effort of many researchers, the people whose experiences are examined run the risk of being reduced to subjects or even objects. Perhaps this can best be explained in terms of the work of Couser (1997) who proposes that a dysfunctioning body poses a threat to the idea that the individual is in control of their own destiny. Through the medium of a dominant discourse these different experiences are normalised and controlled in order to be made explainable, they reduce abnormal experiences into more acceptable models by reconstructing identities. This is illustrated when the ill are depersonalised and their experiences generalised into a comprehensive medical narrative which allows the medical fraternity to 'reinterpret patients' pasts and literally pre-script their futures' (Couser, 1997, p.10).

The biomedical model, which has long dominated the arena of medicine, reduces the sick body into categories of medical knowledge (Lyons & Chamberlain, 2006). These perspectives reduce the sick and disabled to a status of a malfunctioning body, whilst ignoring the many intricacies underpinning health, subsequently implying the ill lack both

capacity and voice (Lyons & Chamberlain, 2006). These perspectives are not only reductionist but in their very nature they prevent the possibility of certain types of information borne from lived experiences of illness that may prove extremely important for the treatment of other people into their paradigm. It seems that when bodies break complex and uncomfortable reactions and responses follow. These very reactions have the potential to further marginalise, obscure, and silence the voices of the ill. There appears to be no space at present for the stories of the individuals who are experiencing illness and disability within the biomedical model (Charon & Montello, 2002; Couser, 1997; Lyons & Chamberlain, 2006) consequently negating the opportunity to challenge this dominant discourse, this seemingly paralysed paradigm.

The need for insider's voices and disrupting the biomedical gaze

From my review of the literature stroke is generally written from an outsider perspective; medical personal, doctors, nurses, occupational therapists, and academic writers. It appears that the insider, the patient and the subjective experience, is generally excluded (Charon & Montello, 2002; Couser, 1997; Lyons & Chamberlain, 2006). An insider perspective is particularly poignant when the patient is an adolescent who suffers a stroke, as this area is outwardly under-researcher both medically and from a personal perspective. Although chronic illness and disability is now considered an area of research which is no longer neglected (Couser, 1997) it seems, as a sufferer of chronic illness and a researcher of such, that each experience is different. Like the patient themselves each illness represents vast diversities. Some chronic illnesses like cancer are symbolically fuelled and carry marked representational differences to other chronic illnesses and disabilities (Couser, 1997; Sontag, 1978). More importantly some areas of chronic illness are better researched and funded than others.

The physicality of adult stroke is researched; however there is an apparent paucity in the research of stroke in adolescence and the overall subjective experiences of stroke. The voices of stroke survivors recounting their personal knowledge of experiences are not kept on medical record. Thus this potentially valuable personal knowledge is prevented from contributing to the existing medical literature on stroke. The expression of the insider's perspective on chronic illness and disability is vital. It is essential that the academic dominant discourse of medicine is challenged to be extended beyond the language of drugs, cutting, and testing to include the language of meanings. It is critical that research includes the human

side of sicknesses, disabilities, and disease. Qualitative health research offers such a vehicle with an emphasis being placed on the insider's experience and view into health. This includes the awareness that medical professionals bring knowledge to the patient, but that the patient also brings knowledge – the knowledge of lived experience of their condition.

Explanation of thesis structure

As the field of life histories on illness and disability is immense I have been selective in the direction I have chosen to go. One of my research aims is to continue the insider voice practice, but from a theorised and academic view that recognises the multiplicities, contradictions, and complicities of being chronically ill and disabled. Our personal narratives are woven into theorised research. I am therefore able to create a text that is collaborative autoethnographic in nature, as well as self-reflexive, and analytical, however, not a study of the narrative data itself.

As this thesis progresses James' voice will emerge, continuing to the conclusion of the study. The structure of the voices in this research closely map the voices between mother and son through his journey toward health. My voice is predominate which mimics the pattern of James' journey. As his mother I was his voice when he was critically ill and aphasic, however he grew stronger and began to speak, reclaiming his language and voice. With the unfolding of this thesis, James' voice is revealed and transformed from a silent observer to his illness to a young man actively claiming and re-defining who he is. Combining our narratives within an academic genre does create a blurred genre. It is intended to be this way in the hope that I may be able to illustrate the deeply nuanced and dynamic story of an adolescent's life interrupted by stroke; and a more thorough explanation to the Reader which may not be attained by using one or the other genre alone. The blurring of stories and genres continues throughout this thesis alongside an emphasis on why this type of writing needs to be done.

Structure of Chapters

The above introduction includes an outline of the focal issues captured in this research and an explanation of the thesis structure. I present the particular difficulties of writing oneself within a collaborative autoethnography of this nature. I take account of a clarification of why reflexivity and insider voices are so important when writing about illness and disability, and how this has subsequently situated my research in this area.

Autoethnography constitutes a form of insider writing that can be produced in an array of genres. It is particularly useful for my research when understood as postmodernist performances within a feminist framework. The arrival at my epistemological standpoint and the rationale behind a feminist driven autoethnographic approach is outlined in Chapter Two. Additionally, my theoretical thoughts are explained within this context, as is autoethnography, including the advantages and limitations of this method when writing about chronic illness and disability. Moreover, insider and outsider perspectives and their utility are investigated.

Chapter Three is concerned with ethics. I address the complexity of ethical issues which are abound in my subject matter. I query whether my research is ethical, and if so, how? Chapter Four moves on to discuss the concept of power. I deliberate how some patients are situated within the biomedical model through challenging this medical gaze. This chapter's content and structural integrity represents our intensity of experiences as patients. It engages with the places where the sick reside, where they are medicalised, and healed. Where bodies are categorised, pathologised, and separated into components of disease. Where the ownership of bodies are exchanged and selves are bartered in for possible health. Where the patient 'buys in' with the hope of a return to health and a return to normalcy. I attempt to capture these tensions and complexities of experiences within this chapter. I also express the positions people assume and occupy within this dominant discourse, and reveal how some possess the luxury and privilege to determine, depict, describe, and ultimately dominate the choices, actions, and responses of others. Conversely, I illustrate how patients unknowingly, or through lack of choice, comply with and are complicit to these inherent operations of power within the subjective positions they have simply assumed or have been assigned.

The central issues in Chapter Five revolve around James' story. The Reader hears his voice as he articulates the experiences of life interrupted by stroke. His raw and powerful words offer glimpses into the world of a broken boy. This chapter tackles sensemaking from the inbetween and liminal space, whilst the move to a more flexible, fluid, uncluttered and dynamic littoral space is offered as the centre of lived experiences. I explore and examine these inbetween spaces; the place where autoethnography thrives (Denzin, 2009). I place James' stories alongside researched and theorised knowledge whereby connections may be made, and I use storytelling to depict James' journey to health. These stories are intended to offer the Reader insight, yet they serve an additional purpose as they also offer me a deeper understanding into my son's experiences. The purpose of the chapter is one of exploration, not to set myself up as an expert.

The concluding chapter, Chapter Six, includes a return to the beginning as I reflect on where I began and the journey to the ending. This chapter includes a reflection on the challenges of collaborative autoethnography with an examination of specific criteria consisting of the contribution this research has made, the aesthetic qualities, and the reflexive worth in addition to the type of impact this work has made and whether it truly represented lived experiences. I also offer suggestions of possible new directions for research, in particular the issue of the taboo illness narrative. The chapter closes with James' voice. This work began with a story about James, and his voice concludes it. He has the first and last words.

CHAPTER TWO

THEORETICAL THOUGHTS

'I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel'. (Angelou, 2013)

I do acknowledge that there are many out there who have more facts regarding psychological theory. There are those who possess the quality of mind to pioneer the way forward, enhancing psychological knowledge, but of my subject matter I have more feelings than them. By no means are they able to experience first-hand my experience and live as the mother of a broken child as well as a chronically ill patient, a woman, and a researcher, with the history that I have.

Through my engagement with the literature I have come to the understanding that knowledge production is informed by ontological questions, the nature of existence and its origins, and the meaning of being (Crotty, 1998). As with any type of research, one's epistemological standing impacts on the type of questions we ask and the way in which we pursue to find and interpret the answers (Unger, 1996). In agreement with Gilbert's statement 'we live in stories, not statistics' the processes underlying this study and the subsequent production of this thesis are based upon a narrative assumption (Gilbert, 2002 p. 223).

On finding a woman's voice

'Science it would seem is not sexless; she is a man, a father, and infected too' (Woolf, 1938, p.139).

I am foremost a woman and a mother. Being a woman has shaped who I am; being a mother has moulded that shape. When I first decided to pursue this story as a thesis I was concerned as to how I would be received by academia due to the particular nature of my subject matter. I was also faced with internal dialogical questions such as how do I explain my position in this story, and who am I in this study? As I outline in Chapter One this research is nuanced and complex. I tell a personal tale of a mother and child, with the narrator being both mother and researcher. I have always been keenly aware that traditional epistemologies appear as a masculine force side-lining women as 'knowers' or 'agents of knowledge' (Harding, 1987). From this male dominated view I was concerned that I would

be perceived, and stereotyped, as a neurotic mother pandering to, and boasting, about her child's accomplishments. I was struck by how I felt the need to defend my position as a woman and researcher, and had bought into the idea that in order to be scientific and abstract I could not muddle up motherhood and scientific professionalism. I was unsure of how to present myself, and felt that I ran the risk of appearing distant and aloof if I portrayed myself too professionally, potentially exposing myself as a detached, dispassionate, and cold woman – an underserving academic and mother.

Upon deeper reflection I realised the need to challenge my taken for granted assumption of how I am positioned, and the spaces I occupy within my culture, society, and community. Although aware of how women have been historically devalued, I had come face to face with it in the polite and subtle halls of academia. Whether this reception was intentional or not, I felt it. The full force of 'cultural shaping' struck home, I had bought into the currency of repression, silence and denial (Harding & O'Barr, 1987). Although this thesis is a story of lived experiences, of lives interrupted by chronic illness, it had introduced multiple layers. It was here that the predicament of holding multiple spaces of a woman, a patient, a professional, and a mother began to unfold. I found I was identifying and addressing inequality whilst I was challenged by my complicity to the status quo and the systems that had maintained it (Gavey, 1992; Harding, 1987). As a feminist researcher I had acknowledged the need to incorporate my experiences of the research process and accepted that in order to tell my story I would be revealing the vulnerable mother and chronically ill patient, but I came to know that I needed to reveal the vulnerable woman.

It follows that feminist ideas support this study. In its most dynamic sense feminism is a form of cultural critique and an arbiter of social change through a pursuit of transformation of relations of power, particularly patriarchy (Elbert, 1991; Hesse-Biber, 2007). Feminism discloses the universalisms of injustices, and acts as a political protest aimed at abolishing exclusionary practices. Postmodernist and poststructuralist feminist strategies allow for a type of rewriting in order to enable the previously suppressed and unsaid other to be voiced. Consequently the importance of other is inscribed into culture (Elbert, 1991; Hesse-Biber, 2007).

Through this research process I have encountered many academics proposing alternative epistemologies and arguing for alternative ways of thinking about the world (Couser, 1997; Crotty, 1998; Denzin, 2003; Foucault, 1982; Gavey, 1992). This call to epistemological exploration includes Parker's suggestion that subjectivities are dictated by hegemonic, scientific knowledge that declares those who do not conform to the accepted

norm as flawed and in need of fixing (Parker, 2005). Through a continued move, which extends beyond patriarchal traditional epistemologies, feminist driven qualitative research empowers subjectivities. They construct an alternative paradigm which promotes feminist knowledge (Code, 1991). Accordingly feminist research allows our subjectivities, our performance, and our interconnectedness to be acknowledged and thus become 'known' in multiple ways (Denzin, 2003; Jones, 2005).

Feminist research demands to be accounted for, and accountable through, a capacity to link personal feelings, experiences, and inter and intrapersonal structures and processes in order to animate theory and research (Jones, 2005). In order to make valid contributions to knowledge, self-reflection and narration are necessary to promote a more human method of enquiry as neither striving for pure theorising or data obtained by pure research alone can be adequate in making sense of self, other, or our world (Allen & Piercy, 2005). Thus, as both a manufacturer and consumer of knowledge I am able to represent as transparently as possible how I generate my ideas and how I know what I know through a feminist approach to the construction of knowledge (Allen & Piercy, 2005; Code, 1991).

It is through challenging established theories and contextual assumptions of traditional scientific research that the true power of feminist research and knowledge construction within social sciences is seen (Harding, 1987). A feminist approach to social science can be briefly summarized as the attempt to increase methodologies, an effort in bringing women together, decreasing established pecking orders, and identifying emotionality (Campbell & Wasco, 2000). It is through reflexivity that experiences can be deconstructed, through reflection how prescriptions from cultures and socialisations have quantified our knowing, and how knowledge changes over time and space and circumstance (Campbell & Wasco, 2000; Harding, 1987).

A common definition of the feminist 'method' calls for reflecting on and representing one's experiences (Harding & O'Barr, 1987). Through this validation and integrity of lived experiences and realities can be accomplished. This is especially so when the status quo reflects an account of reality which habitually discounts a woman's everyday experiences (Allen & Piercy, 2005). Additionally, self-reflexive practice and critical analysis are essential to avoid complacency in how women are positioned within a dominant discourse. At the same time, issues of sanctioned complicity and lack of choice can be acknowledged and understood within this framework. Feminist theories challenge the dominant discourse, and it's dictatorships of thinking, feeling, and reacting within both personal and professional

lives. Feminist academics urge that patriarchy needs to be questioned as it is both out-dated and unfounded, and serves little purpose in a postmodernist world (Allen & Piercy, 2005).

However, these words are easily written. They do not capture my journeying toward my pedagogical change where I am able to acknowledge and challenge not only marginalisation and exclusion, but also my own compliance and complicity to the accepted status quo. I was raised as a member of a dominant cultural group and it was therefore difficult to think about myself as a minority as it is within these dominant cultural groups that assumptions of a taken for granted acceptance of the way things are, as simply correct and natural, are upheld. 'Normalcy' is adopted, and it is only through the development of self and in embracing an inherently feminist self that separation and comparison occurs. These issues became more apparent through the process of my research where I was time and again confronted by the power of dualisms and dichotomous thinking. These binaries communicate exclusionary and differently weighted valued pairs such as male-female, healthy-sick, normal-abnormal, and mind-body (Code, 1991). This has particular poignancy for my research as I propose the importance of subjective meanings and sensemaking of lives interrupted by chronic illness through insider experiences and personal illness narratives. Traditional binary epistemologies have far reaching implications, especially within the medical establishment, as the presumption of this dominant scientific discourse is inextricably tied within operations of power which can be exclusionary, suppressive, and thereby effectively silence voices (Allen & Piercy, 2005; Code, 1991; Harding & O'Barr, 1987; Harding, 1987).

Feminist research allows the silenced voices of other to be heard and recognises stories and voices that have been lost within traditional philosophies of science. Feminist theorists illustrate the concept that human behaviour cannot be investigated without taking into account the specific context within which the individual is located (Harding & O'Barr, 1987; Harding, 1987).

A foundational notion within feminist psychological research is that there should be more active involvement rather than objective detachment, and that researcher reflexivity is key to ensuring that research is sound (Allen & Piercy, 2005). Feminist ideals therefore embrace personal values, biases, and subjectivity which may or may not have an influence on the analysis of results, and suggest that the observer and the observed exist fundamentally on a similar plane (Harding, 1987; Jones, 2005). Thus feminist driven research is not independent of its researchers or bound by its methodologies, but rather it is part and parcel of primary cultural practices (Jones, 2005). The appreciation of diversity and subjectivity

enables barriers to actual and competent understandings of a person's agency, lived truths, and experiences to be challenged (Maynes, Pierce, & Laslett, 2008).

Methodological journey

'Researchers should not be constrained in a methodological straightjacket'
(Chamberlain, 2000)

I wade through methodology to ensure that I am able to capture the layered accounts, the multiple reflections, the width and breadth, and the deeply nuanced and complex issues within my subject matter. This research is informed by stroke, chronic illness, and disability which inevitably fall within the occupied territory of the medical domain. As Chamberlain (2000) articulates, this domain is typified by philosophies of an objective reality. Furthermore, this dominant traditional scientific field upholds the attitude that researchers are dispassionate and removed. These researchers optimise the concepts of prediction and control to precisely measure 'psychological' constructs and variables which can be comfortably pooled with studies of biomedical variables, with a departure from the mind-body connection, and a disarticulation of the physical body from the social context (Chamberlain, 2000). This raises the question of how to conduct research into the subjective experiences, and the meanings of lives interrupted by chronic illness and disability within this type of territory. Moreover, how are psychological questions addressed and health issues researched competently and professionally from a qualitative perspective (Chamberlain, 2000)?

Becker (1993) explains the difference between working in 'descriptive mode' and working in 'discovery mode', as moving further into 'getting inside' the subject matter. For competent qualitative research to be achieved it is necessary through interpretation, inquiry, and self-analysis that the 'inside', the very meanings of experience, are represented to the listener. These representations should not be generalisable but rather provide thick descriptions, reflections, and critical analysis (Chamberlain, 2000; Denzin, 2006); in doing so an interrelationship between storyteller and listener is created. This is foundational in bringing about interpretation, not only the storyteller's, but of the listeners themselves so that they may interpret this story into their own context. Through a process of discovery and interpretation subjective experience is interwoven into long held and dominate attitudes of objectivism and universality of the stamped ground of the medical domain.

For the purpose of addressing the questions regarding competent research I turn to Murray's (2000) explanations of levels of narrative analysis as a structural framework. He

proposes the utility of illness narratives in terms of personal, interpersonal, positional, and ideological, and explains the integration of these levels as a constant shift between self, others, and the social context (Murray, 2000).

At the personal level, narratives are expressed as experiences which allow for expressions of sensemaking. Illness narratives are described as having a personal function for healing and self-care, and it is here that a hybridity of identities of selfhood and sameness, of the need to be accepted as 'normal', the need for validation, and a linking of past and present, socially constructed selves within a storied framework occurs (Murray, 2000).

The interpersonal level of analysis is concerned with how interpersonal processes influence the narratives that are produced (Murray, 2000). In this instance the interpersonal level includes the relationship between researcher and participant who are also mother and child, and our interwoven experiences as told with the 'mosaicking' of stories through a collaborative autoethnographic method. However, I suggest that the interpersonal level of analysis in this instance extends beyond the mother-researcher and child-participant relationship as it is, in part, a protest performance and serves as a process of 'giving witness' in order to disrupt an 'established wisdom' held by the medical field. Moreover, from a postmodernist perspective, there is a social responsibility to share this story (Murray, 2000).

Broader social frameworks and the moral and social functions of illness narratives are more readily understood from the positional level. This story and the production of this thesis did not occur in vacuum. It is at this level that an ever increasing awareness regarding the broader political, philosophical, and ethical conventions which permeate into our everyday lives, our experiences, and stories transpire. In the case of a chronic illness and disability context, space and time are paramount in the construction of the narrative (Murray, 2000) which leads to analysis at the ideological level. At this level the focus is on shared social representation, and how societal ideologies, representations, and beliefs function (Murray, 2000). It is here that narratives supply a medium for constructing and shaping ordinary social experiences, as through storytelling the audience is able to derive meanings which can be placed within their own context. In this way new ways of 'knowing', deeper understandings, and insights are generated which contribute to the development of a reciprocally comprehensible world (Murray, 2000). Thus illness narratives may provide a source of information about lived experiences, but they can also act as a form of validation and advocacy.

Illness narratives are explained in multiple ways. Kleinman (1998) describes them as capturing an insider experience without the arbitration of formal research. As noted, illness

narratives are defined as a form of sensemaking and a form of healing. This type of therapeutic employment enables an understanding of the disjointed, multifaceted, and life changing experiences one is confronted with when one's life is interrupted by chronic illness (Brody, 2003; Bury, 1982; Murray, 2000). Furthermore, through the telling of illness stories the narrator is able to mourn then let go of their old story and re-write a new one. Richardson (2012) explains it as the making and the living of a story whilst representing it. Additionally Frank (1995) suggests that personal illness narratives can serve to reconstruct the fragmented and broken self into a new claimed and accepted self. He also explains how personal reconstruction includes a social one, where the individual renegotiates the spaces occupied in the community in which they live (Frank, 1995).

My research includes the consideration of the ironies, contradictions, pressures, and paradoxes of lives interrupted by chronic illness and disability. This work also addresses alternative and inbetween spaces whilst challenging positions that the chronically ill and disabled assume and/or are assigned and the subsequent changes in self and other. It critiques traditional methods of knowledge construction and addresses operations of power and social power relations within a dominant discourse.

I therefore require a methodology which allows flexibility to move between spaces and address the dynamics of self, other, and voice whilst challenging the socially constructed binary positions that are generally available to the chronically ill and disabled. I also need to consider which methodology affords me the opportunity to merge both academic and personal stories whilst engaging with the literature. Likewise, I require a discursive space to tell our stories and to present my personal experiences of chronic illness in order to conceptualise my son's experience.

Arrival at autoethnography

'For life is not lived realistically, in a linear manner. It is lived through the subject's eye, and that eye like a camera's, is always reflective, non-linear, subjective, filled with flashbacks, after images, dream sequences, faces merging into one, masks dropping and new masks being put on. In this world of reality, where we are forced to react, and life leaks in everywhere, we have nothing to hold onto except our own being.' (Denzin, 1992, p. 27)

As noted above, Chamberlain proposes certain necessities for competent qualitative research to be performed, including the need for qualitative health researchers to capture the stories within the vast amount of statistics which has generally dominated this field of study. Thorne (2011) explains this need due to the overwhelming amount of quantitative research which qualitative researchers need to work alongside. Moreover, Thorne (2011) also highlights the importance of revealing and questioning taken for granted assumptions in order to fill in the gaps so that counter-knowledge is generated. This new knowledge allows for better decisions to be made available for all in the health care arena.

Postmodernist epistemology and feminist theories challenge traditional ideas of authority and longstanding dualist divisions. For example, the professional and the amateur, the insider and the outsider, and the academic and the non-academic are problematised (Campbell & Wasco, 2000; Hesse-Biber, 2007; Richards, 2012). These postmodernist challenges include the idea that there is no universal transcendent truth nor a purely objective teller or listener. Accordingly, narratives can be used in a variety of ways in qualitative health research. With these considerations in mind I am led to adopt autoethnography as my research design.

Autoethnography is a type of phenomenological research which enables a researcher to write about their own experiences, and has significant implications for research into the experience of illness, and for writing illness narratives. Autoethnography facilitates a blending of personal stories and research in different ways. I am able to blur genres to offer the Reader a glimpse into the 'inside' of life with a chronic illness and disability. I can reveal the cultural plots and practices which guide my research and writing. I can convey coherence where previously there has been none. I am able to create meaning whilst embracing the broader structures of our cultural lives which dictate and determine how we tell our stories in a particular way and the subject positions we hold within this framework (Denzin, 1992; Foucault, 1982).

My research is an unfolding process of action and exploration, and I use this means of writing as a journey of discovery, and a means of knowing (Jones, 2005). Autoethnography promotes transparent research and reflexive ways of understanding lived experiences, narratives, and identity issues. However, this is not unproblematic as certain writing criteria and standards need to be adhered to in using narratives appropriately in qualitative health research (Murray, 2000; Richardson & St. Pierre, 2005). These criteria include, among others, aesthetic worth and reflexivity. Moreover, the appropriate use of

academic dialogue is required to make significant contributions to the specific field through an explanation of why the story is told and the impact on self and/or others (Richards, 2012).

My introduction to autoethnography was through reading Ellis' (1995) *Final negotiations: A story of love, loss, and chronic illness*. Ellis explores the deeply complex stories of two lives irrevocably changed by fatal disease. She reveals through autoethnography a story of love, death, and identity, whilst enabling the Reader a glimpse into the complex, layered, and deeply nuanced accounts of these lived experiences. Ellis' remarkable account blurs genres, connecting personal experiences and academic theory enabling others to access these experiences which offer deeper insights and understanding, and a potential for healing.

The direction I have taken with the narratives in this research is collaborative in nature. I write of my son's and my stories in an attempt to reveal subjectivities and highlight the gaps between the medical professionals and the patients whilst also bringing into focus wider social implications. Through story writing I show what it feels like to live with chronic illness and disability rather than simply describing the processes. Although an emphasis on aesthetic worth, subjectivity, resonance, and memorability are not usually found in the epistemological vocabulary of the medical area (Jones, 2005), autoethnography enables me to bridge this gap. Furthermore, this methodology offers an opportunity for telling our personal illness stories which are entwined and confined within the statistics of a medical narrative. I am also able to interlace complex connections between life and art, subjectivity and psychological theory, individual and social, elicitation and enlightenment - facilitating the power in having it 'both ways' (Jones, 2005).

An autoethnographical method gives voice to human agency, to our decisions and actions as we play out in our world. Putting pen to paper in this way empowers 'representation, legitimation, and praxis as part of an ongoing dialogue between self and the world about questions of ontology, epistemology, method, and praxis' (Jones, 2005 pg. 765). Adopting this methodology for my research enables a dialogue to begin in order to find a place for my personal knowledge, for explanations of our lived experiences, and meanings to be expressed and interpreted within our social, cultural, and political lives (Jones, 2005). Autoethnography thus provides a type of outlet for the consideration of specific types of experiences (Richards, 2008). As a writer I am able to freely represent, interpret, [de]construct, and reconstruct experiences. I am able to blur writing genres to reveal the unfolding processes within the production of this research, whilst upholding the power of

insider voices. I am therefore able to avoid what Chamberlain refers to as methodolatry (Chamberlain, 2000; Richards, 2012).

The processes of writing my research in this way is as essential to its meaning as its content, as meaning is shaped through how the story is told (Ellis, 1995; Jones, 2005; Richards, 2012). Through different levels of analysis and reflection I am able to offer the Reader an inside glimpse into the very meaning of having a life interrupted by chronic illness and disability rather than merely offering descriptions or recordings of an external 'truth' (Chamberlain, 2000; Murray, 2000; Richards, 2012). Thus the process of writing can be viewed as having an independent life of its own and separate from the experiences it is supposedly recording, so much so that this text can be seen as being a new type of experience altogether (Richards, 2012). This has weighty implications for narrating life histories, particularly for qualitative health research and the experiences of personal chronic illness (Richards, 2012). Consequently, the production of this thesis is in the process of the writing.

On a personal level this means of expression offers a compelling and powerful emotional, yet cathartic, passage to immersing myself in our stories whilst discovering a pathway to coherency and fuller understanding. The writing is underpinned by psychological theory, interpretation, and reflexive practice which in themselves are forms of sensemaking. It is an act of validation as it allows a move from intangible experience to a tangible text, and a form of testimony bound and immortalised in text. However, for this story to serve an academic purpose, and in order for me to earn the right to use it in this way, I need to illustrate an appropriate depth of knowledge of relevant theoretical psychological materials. Therefore I need to be cognizant of the following issues;

Academic encounters

An overall goal when adopting an autoethnographical method is to use a story to reconstruct a lived experience. I wish to present a realistic view of life through this plotted discourse. However, our story, like life, is nonlinear. It is messy at times without a predictable beginning, middle, or necessarily a happy ending (Denzin, 1992). It is through self-conscious interpretation that the relationship between self, other, history, and culture is explored and the boundaries between become blurred (Chang, 2008; Denzin, 1992). Social forces shape not only groups and communities but also the individual, their sense of self, and understanding their chosen life path (Hiles & Cermak, 2008).

Through reflexive practice and critical awareness I am able to consider and challenge the questions posed about representation, particularly in addressing the socially constructed

binaries in terms of illness and wellness, normal and abnormal, subject and object, and mind and body (Code, 1991). I am able to be both object and subject whilst collaborating with my son, and I am able to move between identities and represent different spaces as I write. However, in order to be transparent and genuine I need to address whether I am subscribing to a Cartesian mind-body dualism if I represent myself dichotomously. Moreover, with my particular research I need to be aware of whether I am reproducing the binaries of individual as the 'object' of psychological study, whilst separating 'others' and social processes, thereby potentially running the risk of not linking the enmeshment of social and psychic life (Hollway & Jefferson, 2013). Am I able to negotiate this predicament through writing about embodiment, interconnectedness, and by confronting my position of observed and observer through continued accountability throughout the production of this thesis? If I am able to achieve this, mine and James' position will be revealed as fluid, continuing, and dynamic, reflected within the influential and reciprocal relationships between self and others within a social and cultural context (Couser, 1997; Richards, 2012).

Additionally, as I noted in Chapter One this research includes a 'well' self looking back into an ill self; a reflection back on ill health. This again has implications for dualisms which need to be expressed in terms of a hybridity of identities, occupying inbetween spaces, and a reflection on more complex selves. Thus, the narrative that I produce needs to convey these complexities, the non-linear, the fraught and the messy ironies, and ambiguities of chronic illness and disability experiences. I also need to remain aware that our story is interconnected. My story is 'mosaicked' with James' story. However, it moves beyond the personal relationship of mother and child, and the professional relationship of researcher and participant, as this story is also interwoven in others' stories, existing within stories of culture, interlinked in community, and embedded in our collective conscience (Frank, 1995; Richards, 2012).

The ill body's articulation in stories is a personal task, but the stories told by the ill are also social...The shape of the telling is moulded by all the rhetorical expectations that the storyteller has been internalizing ever since he first heard some relative describe an illness, or she saw her first television commercial for a non-prescription remedy, or he was instructed to 'tell the doctor what hurts' and had to figure out what counted as the story that the doctor wanted to hear....Whenever a new story is told, these rhetorical expectations are reinforced in some ways, changed in others, and passed on to affect others' stories. (Frank, 1995, p. 3).

I therefore need to consider to what extent is any story truly owned by the individual. Denzin (1999) suggests writing is not an innocent act, as through storytelling I am indirectly adding to, integrating, or creating a counter-story to mine, James', and others' tales (Denzin, 1999; Nelson, 2001; Richards, 2012).

Autoethnographic review

The use of personal stories as the source of research data may create certain disconcertion within academic circles. This discomfort is partially derived from the idea that personal narratives are not filtered by any intervening source; they are messy, complicated, subjective, and raw. These personal experiences are not measured or quantified and constructs are not operationalised and therefore cannot be conveyed in a 'perfect' or 'accurate' form (Gubrium & Holstein, 1998; Lance, 1997). However, accuracy is not the purpose of autoethnographic narrative; rather it is a form of social inquiry with an emphasis on human agency from a human perspective. I write from the understanding that narratives are a shared cultural performance and that no story is independent of its culture or of a larger narrative (Denzin, 1995).

Autoethnography is centred around self-perception, and supports disability and chronic illness studies through preventing objectification and 'othering', and through promoting empowerment, visibility, and giving voice to previously silenced voices. My challenge is how well I am able to convey this particular story. The revealing of researcher reflexivity can be nebulous and difficult to convey, thus potentially affecting the seriousness with which this work is received (Mayan, 2009; Maynes, Pierce, & Laslett, 2012; Richards, 2012). Criticisms of this method espouse exploration through writing as textual showpieces; as texts being entrancing and as concealing rather than revealing. Suspicions extend to suggesting that these stylistic pyrotechnics seem to offer more than what they have, such as claiming that they are making available only certain truths and realities (Lance, 1997; Richards, 2012).

On the other hand, autoethnography is endorsed not only as an ethical discourse which enables one to take a position of moral and political stance in the world, but also as a vehicle that promotes freedom of voice (Denzin, 2003). Furthermore, Bochner and Ellis (2002) suggest autoethnography actually enhances empathy on numerous levels including interactions between narrator and listener as well as between author and participant. I support the endorsement of autoethnography, and an overall belief in common humanity

and psychology's social responsibility. I therefore back the use of a methodology which enables an academic challenge to accepted authorities, and revealing and destabilising existing power structures in order to overcome dominant dogma and to disrupt the status quo. Further, autoethnography also allows for the recognition that some people are marginalised and denied access to belonging to 'normal' accepted mainstream society and are without access to power and resources. Autoethnography can give voice to disenfranchised people and recompense harms (Denzin, 2009). Moreover it has given me the opportunity to express what has previously been inexpressible.

Insider, outsider, or somewhere inbetween

'Do you have to be one to know one?' Fay (1996 pg. 9)

Fine depicts the use of other people's voices to speak a researcher's message as ventriloquy (Fine, 1992). As I outlined in Chapter One, and readdress this issue within an ethical context in Chapter Three, I have chosen to tell my experiences of chronic illness for various reasons. I use my experiences of chronic illness through storied accounts to create context within which James' stories are heard. Furthermore, my insider perspective has enabled me insights, and understandings on a far deeper level of what it means to have your life interrupted by a chronic illness. My research is structured around an insider perspective with an emphasis on reflexivity and critical analysis and is situated in this way as I wish to remain as transparent as possible. I wish to expose my biases and subjectivities to ensure that I do not alter, filter, or tamper with James' experiences, nor attempt to analyse his stories as data. Likewise, I wish to avoid running the risk of derogating and diminishing his experiences, but rather let his stories guide me to engage, analyse, and critique relevant literature in order to add to the existing body of knowledge on illness and disability in order to enhance meanings and develop additional insights into lives interrupted by chronic illness. I therefore do not need to rely on others. Nor do I need to be concerned when listening to another's story that it is indeed meaningfully true and accurate to them. Rather than concern myself with the quality of their memories and their 'trustworthiness' I am able to represent the space between lived experiences and the telling of experiences (Yang Yuan, 2001).

I have considered the suggestions which were raised during the ethics review process of whether I could have selected a more predictable research method. It was submitted that I may wish to interview a number of adolescents with disability and chronic illness and their

families and record their experiences. The notion that someone else could interview both my son and I in order to record our story was also raised. However, my concern was that the richness and depth of the story may have been lost. A fundamental reason for choosing this method is that I am able to think not only as a woman, a mother, and a patient, but also as a researcher, 'psychologist', and writer. I do not set myself up as an authority but rather I explore the underbelly of illness and disability culture to create the opportunity for a discursive space to reveal the tensions which exist but remain unexplained. Our story may not be better than others; however I can represent and present my own story better than I could possibly represent another's. If I had chosen the more predictable option, and knowing what I know, would I stand back to protect the vulnerability of my participants? Would I plunder the depths of their psyche as brutally as I do mine? Although protected by ethical principles of informed consent and confidentiality, would I initiate a process of potential pain, revealing loss, sadness, and grief, and then leave? I would need to consider the possibility of the negative emotional and psychological consequences of having my participants share their life and stories. Would I be practicing therapy without a license (Couser, 2004; Yang Yuan, 2001)?

Through an autoethnographic method and processes of critical reflexive analysis I am able to bridge the gap between life as lived, life as experienced, the life as told, and the life as represented (Yang Yuan, 2001). I need not concern myself with the 'epistemological triangular relationship between teller, the narrative, and recorder of the narrative' (Yang Yuan, 2001). Moreover, occupying the space of insider researcher and being both advocate and sceptic I am able to consider, and complete, possible omissions through my own volition. As an insider researcher I am able to enhance the richness and depth of understanding with an insider knowledge which may be inaccessible to an outsider researcher, raising the question of whether this type of research is only truly able to be conducted from an insider perspective.

Generally, within the medical domain illness is viewed as a 'biological and material occurrence, however the human response to it is neither biologically determined nor arithmetical' (Charon & Montello, 2002, p. viii). Insider perspectives have been explored within qualitative health research and are considered a vital necessity to understanding the patient within the process (Connelly, 2005). Each patient, the 'subject of medicine', and their physicality, emotionality, spirituality, and psychological make-up are all inextricably linked and need to be included within medical study to ensure that they are considered in their totality (Connelly, 2005). Moreover, the individual patient, their mind-body functionality, the

nature of their illness, their beliefs, ideas, values, and culture impinge in an equally inseparable way upon their interactions within the medical field and may determine a vast array of outcomes. The insider researcher may provide additional degrees of dimension, significance, and nuances. Therefore it is largely recognised within qualitative health research that individual patients and their families offer a wealth of experience and knowledge, and may be considered as occasions for insights and deeper understandings (Charon & Montello, 2002). This is particularly important for my research as I propose the essentiality of the insider approach is for allowing deeper understandings of the person in process. As the particular knowledge, experiences, and insights the patient and their family bring are vital components which need to be revealed and accepted as worthy and valuable to medical knowledge. Together this knowledge may serve a common, yet powerful, purpose to heal with a focus on the entire person. Accordingly, the existing underlying tensions between the medical profession and the patient need to be observed. These intervening and splitting spaces ought to be bared, as it is within these spaces that a potential for counter-knowledge may be found, which may enhance existing knowledge.

Additionally, the insider researcher needs to be considered in terms of how they are positioned. With regards to my research, am I too close to my son? Do I muddle my experiences and responses to chronic illness with his? Does my position as an insider blur objectivity, reflexivity, and verisimilitude? Furthermore, insider-outsider perspectives are dualistic in form and therefore not only are they potentially overly simplistic, but again I need to be cognizant of subscribing to dichotomous thinking.

Fay (1996) suggests that the insider researcher is so trapped and tangled up in their own experience that they are not able to adequately distance themselves from the research topic. He proposes that an outsider researcher may more adequately conceptualise the experience from a distant and less enmeshed position. He explains how the insider researcher may be bewildered, and full of confused and mixed up feelings, and at times contradictory goals, views, and emotions. He proposes that an outsider may be more able to see through this complexity and suggests that the outsider researcher is better positioned to reflect upon the wider perspective and draw connections and influences. Fay (1996) lastly laments that people protect themselves from fear and guilt by hiding, and therefore it is difficult to disentangle this self-deception when the researcher is an insider and thus the one who is unwittingly hiding.

A concern with this authoritative outsider academic voice proposed by Fay (1996) is that information in the research topic may be controlled in a linear argument. As Bury (1982)

and Frank (1995) explain, chronic illness narratives are outlined as a linear experience, to disambiguate, to move things along, and to obtain closure. We may seek the reassurance that life is linear, but it is not, and chronic illness in particular does not run a probable pattern. These predictable illness narratives do not allow the problematics of chronic illness to be deeply explored. Moreover, these common and conventional narrative plots may lead to ‘sins of omission’ which may render mute, or subdue voices (Ezzy, 1998). Benet (1996, p. 768), an activist for patients’ rights, eloquently outlines the dangers of generalisation and of using illness narratives in a predictable and linear plot.

‘We are treated as identical packages or ID numbers having textbook feelings. Concrete thinkers reason that if the symptoms or diseases are alike, then it is logical that these patients will feel, think, and respond in kind.... They are unaware or indifferent that people can see their afflictions dissimilarly, suffer and feel pain in varying ways, and yet all be true and accurate in their distinct experiences of the same affliction.... We are not always seen as individuals, and we are not taken seriously enough often enough. How can we bridge this gap and build credibility and respect? What can we do as patients to help those in the medical community hear and attend to our needs?’

There appears to be as many arguments in support of insider researchers as against, with similar issues being raised with regards to the outsider researcher. Each raises important factors which need to be reviewed regardless of whether the researcher is positioned as an insider or an outsider (Dwyer & Buckle, 2009). Regardless of the researcher’s position, the turn within contemporary qualitative research, with an emphasis on interpretation, and reflexivity, places a demand on researchers to embrace humanity and for their research to be ‘part of this world’. Simply put, ‘the social sciences and the humanities become sites for critical conversations about democracy, race, gender, class, nation-states, globalization, freedom and community’ (Denzin & Lincoln, 2005, p 3). This turn has generated profound disquiet as we now need to view the world through a different lens. An individual insider account of lived experiences offers an alternative view which may bypass the common and accepted linguistic ranges of predictable plots and linear patterns that may disambiguate illness experiences, and may also inadvertently oppress and silence voices (Ezzy, 1998; Richards, 2012).

Positioned as an insider researcher I am more able to start critical conversations whilst deconstructing personal experiences and texts. Moreover, an insider position allows me a greater opportunity to manoeuvre the complex process of relating lived experiences in text to the world. I am able to reveal through an insider position how I (de)constructed my ideas throughout the process and production of this thesis. I am able to show that I am not the omniscient researcher but rather I am able to adjust the traditional power relations which exist in research projects and within the field of psychology (Couser, 2004; Richards, 2012). Furthermore, as an insider I am able to capture the many contingencies, complexities, and messiness of living with chronic illness; as I live them. The telling of these stories from an insider perspective is not a linear account but dynamic, they reshape themselves and change through the telling. These stories are alive, they represent both lived and living experiences, and when stories are alive the Reader remains attentive. They attend to the stories that may bother, disturb, and unsettle them, and may argue, disagree, and criticise, but they are listening (Denzin & Lincoln, 2005; Jones, 2005; Richards, 2012).

However I still need to address my concern with the apparently limited dualistic positions offered to a researcher as either being an insider or an outsider. The dichotomous manner of presenting insider and outsider perspectives is not only restrictive but is also overly basic and one dimensional. The idea of an inbetween space challenges the binaries of these positions (Dwyer & Buckle, 2009). Mullings (1999) expresses qualitative researchers' knowledge is underpinned by the understanding of their positionality, and rather than viewing the researcher as either in or out, a dialectical approach embraces an inbetween space where differences are not absolutist. This approach favours a fluidity and flexibility which enables the capturing of the deeply nuanced and complex layers of life and lived illness experiences. It allows for an understanding that although one may possess the same passport this does not imply complete sameness with those people. Similarly, being positioned outside of a specific group does not designate complete difference (Dwyer & Buckle, 2009). Therefore, an inbetween space is more appropriate for my research position; and it is also the space where autoethnography flourishes (Denzin, 2009; Jones, 2005). Adopting this inbetween position is particularly salient as both my son and I occupy inbetween spaces in our lives. These spaces are explored in Chapter Five.

CHAPTER THREE

ETHICS

'Narratives are not just descriptions of feelings and actions; they present these feelings and actions as part of a practice. Narratives are ethical in that they express the teleological nature of practices as endeavors that aim at a common good'
(Josselson, 1996, p. 286)

Introduction

It would be remiss to write about this story and not write about the ethical review process and how it proceeded as it was through this process that my own epistemological standing has become clearer. I have been afforded the insight into how I am positioned within an institution I both respect and admire. Moreover on reflection it was in this arena that a clash of epistemological stances were revealed and I was confronted by ethical issues that I had previously taken for granted as part and parcel of my role as a mother and researcher. However, it became evident that there were a myriad of complex ethical issues and concerns bound up in this research that I had previously been unaware of, and my philosophical considerations regarding my taken for granted ethical beliefs became burdensome. I began to tread lightly and with gloomy trepidation where before I had been confident. I had come to realise the weight of responsibility contained within the dynamics of researcher-participant and mother-son.

Let me start by explaining why I want to do this thesis. I want this story recorded, to validate not only mine but also my son's experiences. I want our story told, I want to make sense of it, and I want to generate further insights and deeper understandings for not only others but myself. I want to write our story as I am aware that the creation of knowledge through narrative differs from other ways of knowledge production. It is different as narrative rationality is unlike propositional rationality (Goodhall, 2008). Storytelling enables the Reader to know the inside of an experience, rather than the how, or merely the description of experience (Chamberlain, 2000; Murray, 2000).

I am aware that I am on a type of narrative methodological quest, but writing about both myself and my son, the participant, is dodgy because it is accompanied by a very unique set of ethical dilemmas. In addition, the type of research my thesis entails may pervert the

scientific criteria of neutrality and disembodiment. Being the researcher, the researched, and the mother of the child participant carries the risk of downgrading professionalism to amateurish informal storytelling or self-indulgent ramblings. The question then is how do I 'sell' our story to an ethics committee? How do I convince them of its validity when I have lost the power of objectivity and the ability to prove causality and test hypothesis (Yang Yuan, 2001)? I present a single case study and adopt human agency as the unit of analysis. I therefore cannot state conclusively how this story may translate to others, or even how it may benefit or serve to add to psychological knowledge.

My thesis is not just a tale of a mother's love and lives interrupted due to chronic illness and disability, but rather it is a deliberate and serious attempt to disrupt the conventional acceptance of what scientific inquiry should be. It is through questions and questioning that it confronts the issues of empowerment, the embodied self, and other whilst it emphasises the standing of women's experiences and the positions of patients as a source of research and knowledge. Our story, this collaborative autoethnography, offers an alternative to systematic and organised knowledge as posed by the traditional philosophy of science. Consequently, it offers an array of opportunities for not only the teller but also the listener to consider a variety of ethical standpoints.

From 'principlism' to ethical care

This research observed Massey University's Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2008). Ethical considerations were closely discussed at length with my supervisor, and ethical approval was granted by the Massey University Ethics Committee - MUHECN 12/091 on the 12th June 2013.

The existence of ethical protocols and the necessity to submit an application to the university ethics review board ensured a foreknowledge of what ethical issues may typically arise in qualitative research, and, in particular, with my research. However, due to my subject matter and the particularities of my research, gaining ethical approval did not necessarily remove ethical uncertainties. The process of ethical review brought to the fore my ethical standing not only as a researcher but as a human being and my role as a mother. How can a researcher not act ethically if the participant is their child? However, it is too simplistic to assume that ethical practice would ensue simply for that reason. If one assumes that ethical practice is inherent in the dual role of researcher and mother than the potential for damage is

increased. It is here that honest and transparent self-reflection is required and I cannot take the position that as a mother I will do the best for my child; that is a hoped for assumption and one most mothers' strive for. Believing you are doing your best does not fulfil nor guarantee ethical 'best' practice.

The completion of the ethical review for my research is not a closed matter. A 'ticked box' does not ensure that all is ethically 'above board' and it is essential that my ethical conduct is constantly in the forefront of my mind. Ethical considerations are at the core of this research. Unlike most research, the relationship between researcher and participant is particularly intimate (mother and child) and the relationship does not end with the research, but involves collaboration with my family and the wider community in which we live. It embraces the examination of intimate family dynamics and contains high levels of self-disclosure. I am also aware that stories are intended for audiences and therefore I have an ethical obligation to the listener and my broader community.

I have found myself challenged by the restrictive nature of applied ethical processes as a one-dimensional model of coherent endorsement and as relegating affect and perceptivity to a distance with apparent little mention of an ethic of care (Anderson & William, 2011; Christians, 2005; Couser, 2004; Denzin 1997; Josselson, 1996). As I said, adhering to applied ethical processes does not necessarily ensure best ethical practice, but rather ensures that I adequately address the complicated ethical issues within my research. I am compelled to elevate applied ethical processes to include a moral domain which includes human agency and action. My beliefs regarding ethical practices, and processes are that they cannot be unpacked into neat compartments of specified guiding values, rules, and facts, but rather as individually self-determined moral compositions, which balance personal freedom, consideration of others, compassion, nurturance, and love (Couser, 2004).

Autonomy, nonmaleficence, beneficence

Autonomy, nonmaleficence, and beneficence are effectively canonised universal ethical principles (Couser, 2004) and it is through these principles that I address many of the issues raised by the ethical review board. This is done with an emphasis on the fiduciary relationship between mother and child enclosed within a researcher and participant relationship. In particular, I address the primary ethical principle of autonomy. My understanding of autonomy from the literature includes the essences of human agency, obligation, answerability, and intentionality, and inherent in this is capacity (Couser, 2004). This includes the participant's right to determine how much of their story they wish to share,

the right to determine the level of involvement within the research project, the right to read what is written, to edit those writings, and the right to withdraw from the research. I am particularly aware of how I represent my son's story as the ethical stakes in this research are high. The heightening of ethical stakes can be viewed as intensifying in proportion to the levels of familiarity and intimacy in the relationship between researcher and participant, in this case mother and child (Couser, 2004).

Much research has indicated the potential for a therapeutic benefit when a patient's story is told (Couser, 2004; Parker, 2005). For example, Murray (2000) asserts that the process of creating a narrative affords the individual an understanding into the disruption caused by their chronic illness, whilst enabling a therapeutic process to unfold through the creation and construction of the narrative. Additionally, the telling of a story may sanction a chance for healing and change if the story is validated (Lieblich, McAdams, & Josselson, 2004). However, viewed within a consequentialist standpoint this may arguably be seen as a matter of the end justifying the means; and from a deontological standpoint as supporting the principle of beneficence over that of autonomy (Couser, 2004). Therefore, my intention is not to claim nor justify the ethics of writing our stories as a therapeutic benefit for my son as I cannot know if that will serve this end, but rather we write to tell a story that is offered to the Reader for them to determine and interpret what they may. I attempt to offer counter-knowledge by engaging with relevant theoretical concepts to address the many questions and concerns of self, other, and our social world when lives are interrupted by chronic illness and disability.

One of my ethical goals is to remain constantly cognizant of the essence of the principle of autonomy. Have I enabled my son the ability to retain both his authentic self and his control in my representation? Have I enabled him to retain his autonomy? In particular I embrace the transpersonal phenomenon inherent in this ethical principle, as through this I am not only able to respect the principle of autonomy, but elevate it. I therefore do not claim lofty aspirations of healing and benefits for James, but instead I offer a colour from which he may use if he chooses to combine with his own palate to shade this part of his life history. Perhaps then I am unable to claim ethical conduct on the principle of beneficence. Rather I rely upon this research to further information and opportunities for transformation. This includes not only an acceptance of our illness narratives, but also an expansion of my personal understandings of my ethical obligations as a woman, as a mother, and as a researcher. I am aware that representing subjectivities may produce ethical blind spots (Couser, 2004). However by utilising a transformative lens I am able to examine a

professional and spiritual merger of principles, practices and processes which promote a holistic and psychospiritual self (Anderson & William, 2011).

The relationship between myself and my participant is different to most other researchers and their participant relationships as there is no time frame imposed on us. I am particularly aware of the on-going and intimate relationship I share with my participant. Due to the nature of this relationship I am not faced with the dilemma of negotiating between an initial primary relationship with my participant which is then later traded in for an intimate relationship with my Reader (Josselson, 1996). Josselson (1996) explains a process of betrayal as she describes intruding into her participant's lives and then leaving them to showcase their experiences to an audience. This highlights an ethical crux from which a multitude of ethical difficulties may arise, such as the abandonment of the participant in addition to using another's experience to fulfil one's own end (Couser, 2004). However, I believe I am exempt from this breach of betrayal of intimacy as I do not abandon my son once he has fulfilled his 'obligation' to the research process.

The ethical codes of practice require that consent to participate in research is informed. Anonymity and confidentiality respond to issues of identification and value, respect and dignity (Gilbert, 2002; Josselson, 1996). Therefore prior to the birth of this research, consent, anonymity, and confidentiality needed to be formally addressed. This is possibly best outlined by a letter I wrote to my son;

Dear James,

As we have been discussing for the last few months I would like to use your story and relate it to relevant theoretical frameworks in order to build on the existing literature on stroke in children and adolescents. We have both agreed we would work together to document your story – using your 'voice' and you will have full control of how much you wish to share. You have said that you are happy to be named, that is, you do not want to be anonymous and there will be full transparency in this endeavour. We have also agreed upon catching up over dinner time to talk about your experiences and for me to ask you some questions. I know that we have been having these conversations for the last three and a half years so this is like going over 'old ground'. In this regard, I want you to be fully aware and absolutely comfortable with working with me as a 'researcher' (not a mum) and you as a 'participant' for my Master's Thesis. As the researcher I will use your experience and look at relevant psychological theories and other research. For example, how a teenager deals with

chronic illness and then compare and contrast your story to what is being said. As your mum I will tell my side of the story from my memories and the diary and other records that I kept, such as photos, school reports, and doctor's letters. We have spoken about specific strategies that I want to write down for you; these strategies are for you so that you feel that you are fully in control and are not obliged to 'work' with me (and no you are not getting paid!!). It is your decision as to which details of your story you may wish to keep to yourself. We have arranged for you to catch up with a family friend if you feel you need someone 'outside' to bounce things off. Your role is to read what I am writing about your story to ensure that I am telling your story the way you remember it. You can read each chapter. If you are not happy with some parts of your story being told you have the right to withhold those parts and I will not put them in my thesis. However, when I write as the 'researcher', that is my work with psychological theories and research; I will need to do it my way for the requirements of my thesis. You are also free to contact my supervisor, Kerry Chamberlain, if there is anything you would wish to discuss with him. You will have access to everything that I write about you and you can ask as many questions as you need to if you are unsure about anything. Most importantly James I need you to know that you are my main priority. I know that you have told me that you want to do this; however, this is your story and my job is to take your experiences of your stroke and research it and theorise about it. We will keep all the information at home and store it in the study and on my laptop. James this is your information so I will keep it for you forever or as long as you wish to keep it.

The ethical principle of nonmaleficence raises questions of whether the writing of this story may cause harm to my participant. Through much self-reflection, and discussions with both my supervisor and James, a decision was reached that this research adhered to the principle of nonmaleficence. However, once again if I accepted this in its purity I would not be doing justice to either myself or my participant as there is always a potential for harm. The point is that whether writing about my son's experience of stroke is not simply whether it causes harm to him or not, but the question is whether the writing is reasonable and warranted, and whether it 'constitutes wrong' (Couser, 2004). I am also acutely aware that this narrative does not solely represent my child, as 'narratives can never contain a whole person, so every act of writing a person's life is inevitably a violation (Josselson, 1996, p. 224). My understanding of embracing the move from ethical 'principlism' to that of ethical

care for my research can be summarised briefly as a move beyond an intellectual adherence to principles and rights, to an emotionality, an immersion in other, acceptance of responsibilities, nurturance, and compassion (Christians, 2005; Couser, 2004). It is therefore important that I embrace the difference between and find the spaces that fill the gaps amid ‘ethical obligations and ethical ideals’ (Couser, 2004).

Whose story is this?

‘Whose book is this?’ Malcolm X in reference to his autobiography (as cited in Couser, 2004, p. 34).

As previously discussed, ethical issues within psychological research practice are significantly critical, however this is especially so when the relationships between the partners involved is meaningfully close in autobiographical collaborations (Couser, 2004). These ethical difficulties stem from the many paradoxes inherent in collaborative autoethnography, such as a ‘dialogical’ process resulting in a ‘monological’ or singular voiced product (Couser, 2004). I am able to represent myself, however this story is underpinned by a life interrupted by stroke and my son’s experience of stroke. It was this event that precipitated this story; therefore I represent his story in my story and in writing this research. I hear his voice, and I record his voice. His voice guides me to certain literature which I interpret, as interpretation is inescapable as stories are representations (Riessman, 1993). Moreover, in the performance of these personal narratives I create different spaces through which interpretation, self-reflection, and analysis occur. I am acutely aware that each individual experience is both unique and dynamic and therefore I do not wish to put my ‘spin’ on James’ story today, as tomorrow his story may change. Our experiences change with an evolving, an ever moving, and on-going process. I can offer a lens through which to view James’ experience, but I wish the Reader to be aware that the lens is murky. It is murky because it contains me in it, my interpretation and my self-analysis – it cannot represent James wholly; not the James of today nor the James of tomorrow. Life is non-linear, it does not necessarily follow an organised pattern with a predictable happy ending, but rather it is problematic and dynamic as its twists and turns back onto itself, a never ending story, and a quest of living.

Narratives on illness and about the disabled deal with stories of people who are disadvantaged. It is this very disadvantaged state where stories can inadvertently expose the vulnerabilities and increase the disabilities and marginalisation already experienced by these people (Couser, 2004). Problems may be exacerbated by an imbalance of power between them, such as the able bodied academic and the sick participant, or, as I am acutely aware in this instance, the power relation between a mother and her child.

Parker (2005) warns about the social power relationships that assume a therapeutic component. Is it possible to untangle the relationship between mother and child, researcher and participant, in order to examine the power relations inherent in them? This line of questioning opens another layer of ethical enquiry and must take into account the adolescent participant. Adolescence is a time typified by internal and external power struggles and identity formations, and this research covers a period of three and half years, a journey through recovery, identify crises and reformations, of power relationships seesawing back and forth, a dynamic, progressing and an on-going process. Thus these questions cannot be answered simply, but rather serves as a reminder of the continuing, and profound moral and ethical considerations which proliferate not only this research but are also intrinsic within the mother and child relationship.

To address these multiple and complex ethical issues I reveal the stories underpinning this narrative. I tell the story of my position, and tell my experiences of chronic illness, my feelings as a mother, and as a woman researcher. As I outline in Chapter One, I tell my stories to help conceptualise James' experiences. I also do this as I wish to show as transparently as possible the how, where, and why I stand in the unfolding of the research process. I endeavour to reveal the processes which ultimately culminate in the production of this thesis. Thereby I am hopeful that the Reader is witness to my biases, my conflicts, and complexities, and at times my tumultuous and overwhelming emotions. I hope through this transparent unpacking process the Reader will understand my ethical positioning and that I have no wish to be my participant's voice or to alter or distort his story in any way. Furthermore, I do not wish to conceal myself as I pay attention to the other in my research, as Fine (1998, p.138) describes researchers who distance themselves from their subjects as 'they recognize no hyphen'.

This story is not just a story about illness; it is a storied account of lives altered by illness. These altered lives can be ethically revealed through narration. Through writing I am able to ascribe meanings to these illness experiences which may have profound implications for others (Couser, 1997; Frank, 1995). This story may act as testimony or as a form of

advocacy for others, and thereby serve an ethical function for society (Richards, 2012). 'Storytelling is for another just as much as it is for oneself' (Frank, 1995, p.17). This research involves not only mine and my son's story but it involves a wider community. This adds another dimension of ethical awareness as Readers may enhance and minimise, create and form a re-enactment of the knowledge in ways that leave it inversely associated and possibly personally relevant (Stake, 2005). Additionally, I uphold the philosophy that research should be of this world, grounded in 'community, shared governance and neighbourliness', thereby serving the community in creating fuller understanding, sharing of views, and opinions, and reciprocal care, whilst fulfilling psychology's social responsibility by making available relevant psychological findings (Christians, 2005). However, this carries further implications for ethical considerations as I need to be cognizant of not only James' well-being but of the message that may be perceived by a Reader.

I am further challenged with ethical considerations regarding my personal involvement in this research as this is also my story. As a researcher I follow a clear cut path of applied ethical processes, however, as the researched woman, patient, and mother, I am not tied by any ethical restrictions as I represent myself. The question is how much of myself am I willing to share and how then do I consider myself, and my personal position, within this ethical process? To address this question I turn to the work of various feminist theorists who are essentially transforming ethical theory (Christians, 2005). I uphold the ideal that social ethics rely upon a multifaceted view of moral judgments being situated as part of human life which extends contextual, cultural, racial, and historical borders (Christians, 2005). Moreover, as noted I place emphasis on an ethic of care where compassion and nurturance resolve conflicting responsibilities, whilst promoting ethical considerations from merely 'doing no harm' to the realm of human care (Anderson & William, 2011; Christians, 2005). Accordingly, I embrace the concept of human care when having to make moral judgments and with my ethical decision making throughout the production and process of this thesis (Christians, 2005). What is more, I also apply this to myself.

Narrating stories for research purposes, and especially this story which contains vulnerable subjects including both the researcher and participant's stories, is a complex, complicated, and variable process. It is therefore evident that it is difficult to subject our life histories to a set of elusive, inflexible, and worldwide principles (Couser, 2004). I embrace a 'recursive' and 'dialectical interaction' to determine and negotiate the relationship between my subject matter for my research, ethical processes and ethical concepts (Couser, 2004). However, I also need to determine what saves this work from being 'pointless self-analysis'

(Goodhall, 2008, p.39). Subjective reflection must be accompanied by epistemological reflection, and through this type of reflection new selves may emerge (Goodhall, 2008; Richards, 2012). I have previously explained I am ethically bound to reveal the underlying processes, however, this needs to include the epistemological processes that shape the production of this thesis. My dilemma is, how much of an argument do I need to make, what form should this take, and how much of the processes of autoethnography do I include (Richards, 2012)? It seems that by concealing processes I am reverting back to the very authorial omniscience academic format which I am trying to avoid by blurring genres and tackling this ‘dodgy’ thesis (Richards, 2012). Crites (1971) explains this by;

‘Among those for whom the story is alive there is a revival of ethical authority otherwise almost effaced in our society. For it establishes on a new basis the coherency of social and personal time. It makes it possible to recover a living past, to believe again in the future, to perform acts that have significance for the person who acts. By so doing it restores a human form of experience’. (Crites, 1971, p. 311)

As this story unfolds, and the deeper I delve into the literature and evaluate my personal values and beliefs, I am increasingly aware that writing is a powerful tool. Richardson and St. Pierre (2005) put forward that one may be challenged by ethical difficulties when writing one’s own story, however, personal writings may also serve to develop an ethical self. Furthermore, they propose that writing is a ‘method of knowing’ and that this process of knowledge development includes an ethical self who is engaged in social action and social reform (Richardson & St. Pierre, 2005, p.959). This is particularly poignant when writing an illness narrative, and especially so with our collaborative autoethnography. Csordas (1997, p. 277) determines that any form of representation is associated with ‘being in this world’. I relate Csordas philosophy to the type of dualism that I find myself in within this research. I am the believer and non believer, I am self and other, and the observer and observed. I am paired within the researcher and participant and mother and child dualisms. Therefore, a further ethical challenge I am faced with is finding a flexible inbetween discursive space, whilst remaining aware of these dualisms and to fully grasp that they are not static, but rather dynamic and representative of subsequent dynamic power structures which are also subject to fluctuation and change.

Lastly, Frank (2000, p.136) articulates the ill self is in a state of continual alterity with the ‘normal’ world. This awareness of ‘otherness’ and speaking for another who is also a

member of 'other' is emancipatory but is not taken lightly as the ethical implications of this project extend beyond myself.

CHAPTER FOUR

PATIENTS, POSITIONS, PERFORMANCE, AND POWER

'In autobiographical narrative performances, the performer often speaks about acts of social transgression. In doing so, the telling of the story itself becomes a transgressive act—a revealing of what has been kept hidden, a speaking of what has been silenced—an act of reverse discourse that struggles with the preconceptions borne in the air of dominant politics'. (Park-Fuller, 2000, p. 26)

Introduction

From a poststructuralist perspective language is situated within discourse. Discourse pertains to an interconnected system of declarations which are linked through a collective of meanings and values underpinned by social factors, powers, and practices, rather than an individual's standpoint and position (Gavey, 1992). It is a comprehensive notion which embodies ways of establishing meaning relative to specific groups, cultures, and historical ages (Hollway, 1983). Through this subject positions are created whereby the individual is afforded the opportunity to respond appropriately, to act and behave, and subsequently develop understandings of self and the world (Gavey, 1992; Parker, 2005). Due to the relationship between discourse, power, and individual subjectivities, most patients, especially the adolescent patient is most likely to be positioned within the dominant and accepted prevalence of the Western medical model.

Moreover, Parker (2005) suggests that subject positions have been situated through a hegemonic Western scientific knowledge, and those that do not conform are deemed defective and in need of fixing. However, positioning is never static; rather it is challenged and disturbed by spaces made available through other discursive opportunities (Gavey, 1992). Furthermore, subjectivities are fragmentary and transitory, and therefore cannot remain wholly stable with a unitary subject position from any one discourse (Gavey, 1992). Hence, change is inevitable. Mainstream psychology positions itself to align with Western cultural expectations of good, healthy, and wholesome citizens in order for said citizens to conform and maintain social order (Campbell & Wasco, 2000; Hesse-Biber, 2007). This patriarchal system is a taken for granted assumption, a status quo within which the person performs, and at times has little insight into the role they have undertaken to perform. This taken for granted

and legitimatised social power relation upholds certain discourses whilst silencing others (Harding, 1987). This is particularly significant for the patient who is positioned within the dominant medical discourse.

Patients and positions

Most patients have access to knowledge, and the subsequent insights, understandings, and awareness has the potential to create the spaces for them to challenge their positions. I have come to know that a patient's position is an evolving and dynamic process which is full of contradictions, problematics, and ambiguities. Both my son and I have been held captured, but at the same time captivated, within the dominant medical discourse. I have searched the literature in an attempt to find a way of articulating the complexities of this experience, however I have struggled to find a way to convey the feelings of being wholly reliant on something that is life giving and has the potential of offering hope and a chance for a new life, yet at the same time feelings of being dismissed, devalued, and rendered invisible by that very same thing. How am I able to articulate feelings of scathing toward something whilst simultaneously that something is saving you? How do I show that how we are socially shaped determines how we respond within this prevailing space? More importantly, how do I convey that at times we are unaware of how we really feel and consequently why we respond in the way we do?

Through my engagement with literature and in my mission to attempt to answer my questions I came across the writings of feminist academic Nicola Gavey and her articulation of the 'unrapeable' woman (Gavey, 1992). In particular, she discusses those women who are not subject to violent assault but rather they are assaulted from a more pervasive, non-recognised, and coercive perspective. This is explained in terms of a woman's position within sexual relationships determined by the dominant discourse which relegates women to submissive and compliant roles. Her study focuses on the operation of power between men and women in heterosexual relationships and, as noted, the 'rape' she discusses does not involve violence or force, instead it emphasises the appearance of a woman's consent and/or absence of confrontation, and includes the women's apparent complicity (Gavey, 1992).

When I read this article I was struck by the way it resonated with me, not only as a woman but as a patient. I substituted rape for another type of assault that I am intimately connected with. This assault, like the rape of the women in Gavey's (1992) article, involves a loss of power, of submitting, of being compliant, and unknowingly complicit, of being unheard and voiceless – of being the good patient. The type of assault I refer to is part of the

taken for granted assumption, the status quo which is the dominant discourse of the biomedical model within which the patient and doctor relationship reside. This assault includes an insidious, complicit, coercive, and pervasive, but an un-assumed, rape of power and autonomy, and at times dignity. However, with the chronically ill and disabled there is an additional violent intrusion, a rape by the illness itself which plunders, ravages, and invades the person without thought or conscience.

Through my experience of chronic illness, and my on-going relationship with the medical field as a patient and the mother of a child patient, I am acutely aware of the subject positions that are created within our culture. However, our positions as people with an illness are further complicated by the illness itself. Our choices are further limited by not only interpersonal power operations and practices between the patient and medical personnel, but within the patient as well. This intrapersonal battle includes being held hostage by an illness that is at times reduced and quiet and at others cruel and unrelenting. The power relationship between the doctor and patient is therefore subject to the ever-changing grip the illness imposes on the patient. This intra-psyche clash can show as transitions from a patient who can articulate their position, discuss, evaluate, and at times argue their corner to a voiceless, submissive victim who lies passively offering up their body in the hope of healing. Regardless of which position the patient takes it appears that it is not determined by them. It appears that they do not have the control to decide, and determine their actions within the context of the patient doctor relationship, rather they are dictated to by both their illness and a myriad of factors, including gender, age, education levels, and the cultural and social contexts that they have been shaped within (Lyons & Chamberlain, 2006).

Power and performance

I have long been aware of my defective and precarious body and my vulnerabilities. Even when I am in remission, like my son, we are still different as we reside within broken and altered bodies. Our bodies lie outside the social construction of what a normal body should be. I have therefore always chosen carefully to whom I tell about my illness story, and I have always faked my normality. I am able to do this as my 'illness' is hidden and therefore no-one knows unless I chose to tell. It is my right to choose if I tell, and to whom I tell. I am well aware that I engage in practices of concealment which disrupts the social regulatory gaze and which enables me to cope. This is my power.

However, this research journey challenges my concealment and faking. Furthermore, in bringing this to light I am struck by my observations of my son engaging in similar behaviours. I observe his personal power struggle as he reclaims his body and takes back control. He fights the presence of illness in his body, and seeks power through public performance allowing him to escape from his body being continually problematised and pathologised. This is his power.

Through the performance of this collaborative autoethnography I have found a vehicle for our voices and the freedom and power to narrate experiences which have previously been ensnarled in cultural and social factors within a dominant dogma. Through collaborative processes I am able to dialogically engage with our illness experiences and produce critical reflections of self and others. Moreover, critical agency has promoted deep analysis of the 'multilingual' facets of self and others and the spaces we occupy in our societies (Spry, 2001).

So with this performative means, and as a patient writing about my son, another patient, I am able to explore the operations of power and social power relations which have not only informed and shaped my identity, but that of my son as well. It is these identities which enable us to make sense of our worlds, however I am also aware that through storytelling I have created changes in representations which have in turn created changes in identity[ies] (Turner, Oakes, Haslam, & McGarty, 1994). My concern with this is that with any identity shift or other identity notions within the patriarchal dominated biomedical field leaves little space for technologies of self. Rather, this field is governed by technologies of power which regulate the conduct of the individuals who act within it (Foucault, 1982).

Denzin (2003) suggests performance promotes a critical analysis of social and political factors through which the practices and politics of human experience can be understood. Through performance, embodied and lived experiences are evoked within an academic format. Moreover, this performative collaborative autoethnography enables me to operationalise the epistemic/aesthetic praxis as a means to examine the concepts of power as pertaining to the tensions between the self and other, within illness and wellness, and within the doctor patient relationship. I use the following storied accounts to summon the corporeal, bodily, and political nature of chronic illness and disability experiences. This includes revealing the interpersonal and intra-psyche struggles faced by the chronically ill and disabled.

Stories from under the biomedical gaze

I have turned to a variety of doctors and medical specialists over the years as a chronically ill person, and then again I have sought their help as the mother of a chronically ill child. I wish to share excerpts of remembered conversations with some of these professional practitioners. These medical specialists are identified by their knowledge; they display their labels of expertise on their white coats and the many letters after their names. They are the 'knowers', the 'givers of knowledge', and through their scientific expertise they have the right to label others, to create and change names (Defenbaugh, 2008).

'And yet, the one who names, who works within language to find a name for another, is presumed to be already named, positioned within language as one who is already subject to that founding or inaugurating address . . . that the very possibility of naming another requires that one first be named'. (Butler, 1997, p. 29)

December 2006

'Am I going to die?' I ask my doctor.

'We all die someday – you may just die sooner'. He replies.

'So what is actually wrong with me doctor?' I say

He responds; *'I can't give you a fancy name – you simply do not have enough bowel to sustain life. I cannot cut again, so if you get sick there is nothing we can do'.*

'I'm not sure I understand' I query.

'Well look at this way, usually if it looks like a duck and walks like a duck and it quacks, then generally it is a duck. But..... we are not sure of your type of duck'.

He begins to laugh. I realise this must be a joke so I politely join in to show that I understand and that I am grateful that he is spending the time trying to explain my predicament. I go for a tinkling laugh, light and airy, but I notice it has a shrill tone to it - high and brittle, but I continue to 'tinkle' along to ensure that he appreciates my compliance and my gratitude for his caring for me. I buy in, I am complicit in fulfilling my half of the bargain – I am the good patient.

I leave the office feeling fragmented, vague and somewhat numb. I suppose that is not an unusual reaction when you are confronted by the idea that an unknown duck may be the death of you.

Up until recently I had not been aware that I had bought and paid for a front row ticket to this egocentric Western show. In alignment with Gavey's (1992) article, I was finally confronted with my own complicity. However, all stakeholders ultimately determine their position within the show and thus arguably through knowledge and understanding ultimately can change it (Shields, 2012).

Furthermore, my front row seat afforded me a position from which to examine James' position as a chronically ill adolescent. As with gendered perceptions of complicity within a dominant patriarchal system, parallels may be drawn from the feminist perspective of compliance to an adolescent's complicity to their marginalisation and rape of power within the biomedical discourse. This occurs through the paradigmatic prescriptions of positions that are assumed between doctors and their adolescent patients, including professional ventriloquism whereby the person (the adolescent patient in this case) is simply by-passed in the process (Carter, 2002). The adolescent is not only silenced, but is complicit in their silencing. They are silenced as they observe their experiences being articulated by others perceptions of their experiences (Carter, 2002). The power that the medical professional wields over the adolescent represents both an institutional and an adult authority of power (Tates & Meeuwesen, 2001). Hence they are silenced; compliant, complicit, and controlled by the subject positions they are assigned. James is unheard because of his severe aphasia, and he is silenced by his complicity to a dominant discourse. He is silent and polite, complicit and compliant. He too is a good patient.

Although an 'ill' person may assume the complicit position of the good patient it needs to be understood within the material context of being chronically ill and disabled and the lack of choices therein. The choices one is offered lie between potential recovery or continued ill health, and, at times, life or death.

Struck down

June 2008

(Continued from Chapter One)..... My cell phone rang fifteen minutes later. It was the school nurse. 'Please come quickly the ambulance is on the way, your son has collapsed'.

I arrive minutes later, following the ambulance into the school grounds. I run towards the sick bay. Stillness has come over me; it has a deadening affect, it is a type of stillness which goes through you, cold and quiet; a dead stillness of nothingness, and there is

a heaviness that pulls me down. I feel like I am carrying leaden weights on my arms and legs. There are no thoughts. I do not want to think. I will myself into the numb nothingness but I move very quickly. I find my child lying on the bed in the school sick bay. I can see straight away that something is very wrong. He is half on and half off the bed, huge eyes staring up at the ceiling. It goes beyond any fear that I have ever felt before. It is an ending, a sudden dreadful stop.

We race across the Harbour Bridge. Please God get us there quickly, I pray. The ambulance is travelling very fast, its lights on, weaving between the traffic. My son lies still. Deathly pale, with glassy eyes staring unseeing upwards. We are racing towards the hospital. Straight into the arms of the medical domain, the sterile places of an antiseptic and paralysed paradigm – a sanctuary of safety. Help my child. Heal him please!

CHAPTER FIVE

JAMES' STORIES

The battle for James

Hospitals have their own sense of time and space. I feel like I have entered a type of littoral zone and am left waiting at the edge of a great metaphorical sea. It is a zone that is not one thing nor another. It is a senseless no-thing. There are no certainties nor absolutes. The littoral zone is where the sea and land meet and change continually. It forms a blurred and messy edge, and it is on this threshold that I wait, praying for my love, my child, to live. Please, please live. I wait endlessly and watch the mute shell of a boy staring with glazed eyes, lying motionless on the hospital bed. I hang onto every words uttered by doctors and nurses, but they cannot offer comfort as they do not know. There are no answers.

Over the next few days my child starts to emerge from the crippling effects of the stroke. Slowly the essence of him begins to appear for a few minutes at a time, then recedes back and he is gone again. Gradually he begins to try to communicate with us. He uses grunts, smiles, and gestures. He regresses to a baby, and wants us to hug, kiss, and hold him. He loves us, he seems so happy. My fourteen year old boy is wearing a nappy. He is being cradled and rocked by me. Yes I can do this, my boy is alive and he seems happy! Then, after holding my breath for days, I finally collapse. No! I cannot do this. I cannot breathe. Not my child. I do not want this for my child.

James is paralysed down the right hand side of his body and he holds his right hand curled up into a claw-like fist. The right side of his face has collapsed. He has lost his ability to speak, and when he tries to talk he produces garbled nonsense. The extent of cognitive damage is unknown. His nasal gastro tube is removed and he is slowly re-introduced to solid food, however, he struggles significantly with eating. He drops food out of the right side of his mouth and cannot feel it, so it sits there until I, or someone else notices and wipes him clean.

I stand helpless as watch my son struggle to talk, to walk, to eat, and to clean himself. An elusive fluid haze of horror permeates my being. I am grief stricken. I mourn the loss of the child I know. I am the mother of a wounded and broken child. I am plagued by his abjection (Kristeva, 1982). The abjection of mother and child is not definable. I jerk and twist between shock and horror. I feel as if I am encased by an explicit monstrosity. What had

meaning is now meaningless and misshapen. My child and I are rendered separate and different; we are no longer 'normal'. We have become something that I do not recognize as a thing. I am crushed by our separateness from ordinary. We are moved to an edge of an unknown reality, a ruthless misery, where abject and abjection are the norm (Kristeva, 1982).

'I think I'm talking. I am saying to my mother let's go to a better hospital they don't know what they are doing here. I am scared. I keep waking up and then blacking out again. I feel horrible. Inside my head there is so much activity. My brain feels weird. I can't settle. I need to do something. Cos If I'm doing something then I don't think, and when I don't try and think then I forget my brain isn't working and then I don't feel. I'm like a T.V that isn't tuned properly. A computer with a virus'. James explains his first few days of consciousness.

Adolescence and the abject body

If the body is something that people do then it is in the doings of people—not their flesh—that the body is embodied; an active process by which the body is literally real(ized) and made meaningful. The body is wrought of action and interaction in situated social encounters and often by means of institutionalized ritual. In communicative action the body comes to be. (Waskul & Van der Riet, 2002, p. 511).

James' voice represents the embodiment of his once healthy body collapsing into the abject. The impact of the stroke has broken beyond the normative boundary of the perceived healthy adolescent body. His body has fallen into abjection where it is smashed and shattered, and where he is rendered powerless. He has lost control. His substance leaks out. His self is under threat. His out of control abject body terrorises the mandate between self and body (Waskul & Van der Riet, 2002).

Meaning collapses, and only the intolerable and unthinkable remain. The abject body presents only one quality, and that is it stands in opposition to him. He remains for days on the edge of non-existence, his black out space, and moments of consciousness which he does not want to acknowledge as it may annihilate him. Rather it is in this early stage that the abject and abjection are his safe haven. He is delivered into peaceful oblivion by this unbearable and inconceivable horror (Kristeva, 1982). 'Nothing is familiar, not even the shadow of a memory' (Kristeva, 1982, p. 5)

Bristow (1997) explains how the body represents the physical site of identity and how this is socially constructed. Brendin (1999) argues about a subjective and inner representation about how a person thinks and feels about their body. She articulates that individuals' subjective realities regarding ownership of their bodies are embedded within the realm of body experience and a body language which is beyond conscious thought and language (Bredin, 1999). However, what happens when the body collapses into abjection? What must it feel like when one is driven to seek oblivion over annihilation? What happens when conscious thought and awareness are terrifying? What is it like when you believe you are speaking, but you are not? What happens when you realise others cannot listen as you do not have a voice? How must it feel to experience a catastrophic malfunction of body and mind? What is it like for an adolescent boy who has been assaulted in the playground of his school, and has subsequently suffered a significant stroke?

Adolescence is a developmental period typified as a period of rapid growth, within which youths form and reform their cultural identities (Erikson, 1980; Fine, 1994; Way & Robinson, 2003). From an Ericksonian perspective, identity concerns the realisation of self occurring within a social context and therefore it is accompanied by important socialisation processes (Erikson, 1980; Suris, Michaud, & Viner, 2004). When an adolescent experiences a life shattering event, such as a stroke, it results in them having to renegotiate their identity across multiple terrains. They face challenges of adapting skills, capabilities, and strengths in line with prevalent roles, and structures characteristic of the society in which they live (Bosma & Kunnen, 2001).

Arguably, adolescents are most attuned out of all age cohorts to comments and judgements from others (Sirin & Fine, 2007). They are sensor stations for rays of conventionality within their accepted norms, and are acutely aware of what constitutes contraventions to those norms (Sirin & Fine, 2007). It is then anticipated that the adolescent will not only judge others but engages in self-judgement. Cohen (1999) describes this as self-policing. Foucault (1997) explains his notion of the panopticon as representing the powerful, pervasive, and intense institutional observations, and, like Cohen's concept of self-policing, it is a social prison where all are seen and judged and where all are taught to watch themselves and observe others. For the adolescent who is crippled and rendered speechless by stroke he stands not only before the external hegemonic social and medical gaze but also before his own watchful judgments. Therefore when an adolescent fights for a re-integration of their social identity, and re-emergence into the accepted dominant discourse, through areas such

as, re-enactments of social roles, structures, and performances the potential for psychological fallout is great.

I became ill in my early twenties. I had passed through the tumultuous, and, at times, fraught years of adolescence by this stage. Therefore an appreciation of the above theories outlining experiences of adolescence has given me a more complete view of what it must have been like for James. I now understand why he would observe his friends interacting with one another with such intense concentration. It appeared as if he was trying to decipher how he needed to be, and act in order to be accepted back into the adolescent impenetrable fold. At times it looked as if he mimicked their behaviours. I would watch as he laughed along with them but I knew he had missed the punchline.

Sensemaking from within the liminal space

How do I best articulate James' experiences of stroke so that the inside of the story, the very meaning, can be told? How do I split and disambiguate the many paradoxical accounts in order to make them understandable whilst avoiding the risk of tending toward a predictable illness narrative pattern? How do I tell of horror? How do I write about love? Is it possible to show the disappearance of a loved child, and their re-emergence into a new self? How do I tell a story about lived experiences when the telling itself becomes another lived experience? How do I attempt to make sense of the senseless? James' experience of stroke resulted in a re-arrangement of lived spaces, time, relations with others, and himself (Bendelow & Williams, 1995).

In order to address the many questions I raise, I create a type of inter-textual discourse to explore and answer these questions through narrative. Storytelling can form a meta-textual landscape, integrating a liminal space which may offer glimpses into James' experiences (Richards, 2012). Moreover, the revealing of these liminal, or inbetween, spaces enables storytelling from 'the frightening no man's land' (Kleinman, 1988, p 181; Richards, 2012). This discursive space facilitates an understanding into the powerful processes of accommodation and adaption that the ill experience during their illness trajectory, through the categorisation of complex and deeply nuanced experiences (Little, Jordens, Paul, Montgomery, & Philipson, 1998).

Liminality is a concept which originates from social anthropology. According to Van Gennep (1960) liminality is a temporary state which means 'of the threshold'. He observed through his study of rites of passage a person who enters a series of phases including separation from society in order to prepare for purification, transition, and reintegration into society (Vann Gennep, 1960). This temporary withdrawal from society, and the move to the threshold, can be paralleled with illness. The ill person is isolated through hospitalisation, and there is a period of withdrawal whilst healing occurs. They are then expected to return to their societies having acclimatised to their new state, and to continue in, or to occupy, new and accepted social roles. Thus, liminality can be thought of as a type of ritual state that enables a person to change from one social form to another through an intermodality of socially enforced structure and antistructure (Turner, 1979; Vann Gennep, 1960). However, illness tends more toward a liminal condition, not a ritual one. It is an imposed social construct not a natural manifestation which enables others an understanding of the social changes the ill person encounters (Richards, 2012).

Researchers have described survivors of a chronic or catastrophic illness as residing in a liminal space (Crowley-Matoka, 2005; Little et al., 1998; Richards, 2012). It is accepted as a temporary state from which reintegration back into society naturally occurs (Little et al., 1998). Turner (1979, p. 94) terms the liminal as a space 'betwixt and between the normal day to day cultural and social states'. He continues to explain how performance within the liminal space enables changes or overturns of identity, and or individual or social roles. Moreover, within these occurrences time itself becomes liminal (Turner, 1979).

Some stroke survivors can be seen as being both apart from and part of their communities. Those that are still chronically ill are impaired and/or disabled can be said to occupy a liminal, or inbetween, space. Frank (1995, p.8) explains this inbetweenness as survivors of chronic or serious illness holding membership of a 'remission society'. This proposes the notion of a secret sub society encapsulated within communities in which some people belong, waiting for their re-integration back into society (Richards, 2012). Moreover, Sontag (1978) describes having to hold two metaphorical passports for the separate realms of the ill and well, however those that occupy the inbetween, the liminal space, hold no passport. Further, for certain stroke survivors the liminal space may not be representative of a temporary state or a holding pattern as they wait for resolution and re-incorporation into their society as these individuals may continue to live in a state of sustained or persistent liminality in which they may function indefinitely (Crowley-Matoka, 2005; Little et al., 1998). This sustained or persistent liminality can be placed alongside Kleinman's (1988, p 181)

‘frightening no man’s land’ as the occupiers of this secret sub society, those that reside in an on-going liminal space hold no ‘passport’ (Richards, 2012; Sontag, 1978). Moreover, they are unable to re-enter their communities and take their place in ‘a fully ‘normal’ life of health and productivity’ (Crowely-Matoka, 2005, p.7).

It is from this space that James’ stories emerge as he represents a ‘liminal persona’ where he holds health in one hand and sickness in the other as he stands stuck inbetween. His story includes a type of hovering between Western culture’s determined binary constructs of abled and disabled bodies and the normal and abnormal person, however he is unable to easily occupy either binary. Thus, he creates his own space within the liminal, his own individually accepted norm where he is able to perform and function, and becomes his own ‘normal’. However, his movement towards ‘normal’ within the liminal space does not neatly progress through stages or phases as outlined by Van Gennep (1960) nor does it abide by Turners (1979) notion that through occupying the liminal space a person is able to invert identity and/or individual or social roles. Rather, James’ experiences of liminality represent an on-going, dynamic, and variable state (Little et al., 1998). It is also clear from James’ experiences that he did not become his ‘pathologised label’ which may have made it possible for him to create flexibility in term of self and disability. Some research indicates that labelling inherent in certain chronic illnesses produces and preserves liminality; and that persistent disability is not a clear indicator that the individual may experience on-going liminality (Little et al., 1998). It appears that James has made this choice whilst accepting his self as he continues along his life trajectory, albeit with interruptions.

James within the liminal

Kleinman (1988, p. 20) writes of hearing of news of cancer as;

Cancer is an unsettling reminder of the obdurate grain of unpredictability and uncertainty and injustice – value questions, all – in the human condition. Cancer forces us to confront our lack of control over our own or others' death. Cancer points up our failure to explain and master much in our world.

Kleinman’s description of cancer can apply to the interruption of meaning and confrontation of one’s boundedness of time and space when one suffers a significant stroke. James first entered his ‘black out’ stage of acute liminality at fourteen years of age. His altered levels of autonomy, rational performance, physical and social competencies, and psychological form resided with him within this ‘black out’ state awaiting for re-integration

and re-emergence not only into self but also back into his social world (Little et al., 1998). It is evident from my observations that this state symbolises an incoherence of subjective time, space and self. Hawking (1975) wrote of 'black holes' in space, within which our understanding and accepted concepts of time and space do not exist. I use the black hole metaphor to enable an understanding of James initially entering the liminal space, as he terms as 'going into black out'. From this black space there is no rational sensemaking, and there can be no prediction or certainty. It remains a mystery to those who stand outside as only hints can be expressed from within the blackout space.

'I wasn't me at times, I think that was when I was in black out. In the beginning I did believe I was going to die, but I wasn't scared. It felt like it went on for a very long time. Later I got these like sensations at the same time, like boiling hot and freezing cold and I started climbing out the window. I had to get out. I remember that I liked standing under the shower in the hospital cos the water was soothing. It stopped those shooting sensations'.

Gradually James moves into a convalescing phase within a sustained phase of liminality. This move includes a reassertion of a semblance of control and need for autonomy with an ever increasing awareness of his 'stroke-patient status' (Little et al., 1998). Frank (1995, p.136) explains this phase of liminality as an 'oscillating trajectory' where the patient is confronted by a sense of boundedness of time, space, power, and social implications, and is typified by a move between a sense of resolution, and then a ricochet back toward the disruptions and despair of the more acute liminal space. Or, in James' case, a move back again into his blackout phase.

Like up until then I didn't even realise that I was paralysed because I was too busy feeling freaked out. I didn't even notice that my foot was screwed. It's funny I can't even feel it if I stand on a thorn. I think I first started realising that it is different now when I knew I couldn't be a cop anymore cos I can't use a gun. I don't feel sad; I just sort of transitioned out of it and didn't think about it anymore. I know I look funny I mean I lose control when I walk cos if I don't look down at my right leg it crosses over the left leg and trips me. I know what it feels like when you can't perform things'.

This state of sustained liminality has been explained as a protracted contention between self and body, where the patient endeavours to develop meanings, understandings, and acceptance of the corporeal elements of their broken bodies (Crowley-Matoka, 2005; Little et al., 1998). These processes of adaption are continually framed and re-framed under a continual surveillance conducted by themselves and the medical and social gaze. James is living with a constant reminder of his 'patientness', where he experiences his body as a site of unfamiliar and unpredictable distress. He is torn and alienated from his previous 'normal' embodied self (Little et al., 1998).

Liminality is characterised by both transience and boundedness (Turner, 1969; Van Gennep, 1960). It represents the attempt to order, control, and interpret anti-structure, but in itself is not anti-structure rather it is a methodical management of safely transferring a transitioning from one structured state to another (Richards, 2012). In this way liminality is in part ritualistic. It enables others to understand how a person moves from one position to another within a society, such as the transitioning from boyhood into manhood. Although chronic illness or disability is not part of a ritual condition, it can be understood and represented as one to some degree (Richards, 2012). Perhaps if James underwent a successful and worthy ritual of reintegration he could claim a new identity. He could re-enter society and occupy a respected and elevated position. However, what would his new identity be, the survivor, the conqueror, the brave, or the man? Further, these identities cannot capture who he really is or reveal the whole story.

It could be that James, like myself, entered a type of littoral zone. Littorality may more accurately symbolize James' experiences than the liminal or inbetween space, as it transcends the medical arena, and offers possibilities beyond stroke and disability. Although the littoral space is a messy and blurred threshold it can be also be seen as a space which is not bound up within the 'subject of medicine', but rather it enables an expression of subjectivity of experience unencumbered by medical jargon and baggage (Connelly, 2005; Richards, 2012). As James is more than just a boy who had a stroke.

Moreover from this littoral space an embodiment of the idea of a perviousness between bodies, and a more dynamic and fluid self can occur. Additionally, within this space a cohesive and fully functioning person can remain as the implied normal, however with a recognition that this standard is not normal but normative (Shildrick, 1999). There are no givens nor foregone conclusions within the littoral zone. Yet it is this very idea which has the potential to connect us to all humanity as we travel life's journey, although conceivably this threshold becomes clearer when you are living with chronic illness and disability (Richards,

2012). Nevertheless, the littoral zone like life is never stagnant. Rather it represents the potential of promise, hope, and flexibility, as it is a space which is always subject to change.

Comment [KC1]: This is a phrase not a sentence!

The road to recovery: Insights into James' journey to health

The following stories in this chapter offer insights into James' journey. They also form part of my journey into a deeper understanding of my son, James' experiences, and his striding towards his new self.

A journey to recovery comprises deeply complex and elusive phenomena. Although I have also made this journey time and again, I wish to state that I have not resolved the many issues, and varied occurrences one encounters on this long and arduous passage. However, I attempt to develop, and offer insights into James' journey back into reclaiming a 'new' life. I investigate how he embraces a broken, and fragmented self into the creation of a coherent and functioning biographical body (Faircloth, Boylstein, Rittman, & Young, 2004). I adopt various foundational theoretical frameworks which enable an investigative vocabulary, and a discursive opportunity into the discovery of the deeply nuanced subjectivities and attempts at meaning making as told by James. Despite months of research, analysis, critical self-reflection, and reflexive practice the following does not offer a completed story. Rather I attempt to dismantle the pain, shock and horror whilst reassembling the shattered fragments of a young life disrupted by stroke. However the act of narrating the trials and tribulations of his journey back toward health empowers James, and ensures that he is no longer trapped by the place of illness that has colonized his life for the last few years.

Bury's (1982), seminal work on the experience of chronic illness provides a conceptual framework for explorations into such journeys. Bury proposes chronic illness as a biographical disruption, an event which disturbs the ongoing biography of the individual (Bury, 1982). Chronic illness disrupts the very structures of everyday living, and the progressive dimensions of the individual's life, and directly shapes the person's responses to these bodily distresses (Faircloth et al., 2004). Pain and suffering shake the once deeply held existing knowledge structures that the person has about their self, body and body functioning (Faircloth et al., 2004). James later explained to me that his stroke changed the way he thinks. He also said that he realized that there were things he wanted to do with his life that he now knows and accepts that he cannot, and will never be able to do. In line with Bury's concept of a biographical disruption James' life has been disrupted. His life trajectory has

been altered. James' stroke has ultimately dislocated him from his once accepted and comfortable determination of who and what he is. It tore him from his life.

Extending on Bury's concept of biographical disruption, I focus on the very mechanisms on how James' reframes his damaged and broken body into an accepted, and coherent socially conformed entity. I weave the theoretical notion of biographical accommodation, which explains the work the patient performs to offset the disruption resulting from chronic illness, into James' experiences (Corbin & Strauss, 1987). Moreover I scaffold Gubrium and Holstein's (1998) concept of biographical work around James comments and articulations in order to offer understanding and insights. Biographical work is explained as a whole life being an interpretive achievement which is continued and adapted through social interaction. Thus it has the potential for flexible and unique adaptations through the interpretations that the individual patient assumes from mediated discursive milieus and social interactions (Gubrium & Holstein, 1998).

These concepts offer a theoretical view into chronic illness and a journey to health. They also enable me to wrap up pain, grief, loss and mourning into a more coherent and tangible understanding.

However, I am still left wondering how much of James' experiences have been molded, shaped and influenced by accepted medical practices, social, cultural and gender expectations. It seems as if he learnt very quickly from the medical practitioners that he must not moan nor complain as his condition could have been so much worse. Instead he understood that he should be appreciative of how well he is doing, and for their treatment. He also knew as a young adolescent male that he needed to correctly perform in order to be re-accepted back into his teenage group. As the Reader will see in the following stories James followed the predictable patterns of biographical accommodation and work. He clawed his way forward whilst he pitted himself against the odds and staked his claim on his self. James is the very epitome of the Western ideal of the brave and stoic patient. He has learnt to hide and conceal his post stroke body with aplomb.

The body as a social construct: The body as social judgment

By the time James returns to school he has become adept at concealment. He appears normal, but is plagued by crippling fatigue, cognitive deficits, and pain. He is able to hide the internal destruction and cognitive and psychological chaos wrought by his stroke. However, he hangs above the 'frightening no man's land'; hovering between ill and well. Like a new

settler he yearns for the land of his birth, while he struggles to adjust to this new and foreign place. He faces these challenges alongside a continual scrutiny of self-policing, ensuring that he does not reveal himself as something other. He strives to safeguard against contravening conventionality (Cohen, 1999; Foucault, 1997; Kleinman, 1988; Richards, 2012).

'I can't do so much – I'm tired all the time. But I just have to do it. I mean I have to go back to school. I'm failing and I'm tired, so I just hang out with my friends at school. I don't learn anything cos I can't remember. But like I'm back at school and back with my friends'.

Although James's words in the above caption highlights the devastation of a biographical disruption they also illustrate the theories of biographical accommodation and biographical work. He is compelled to go back to school, as within this space a new biography can begin to take shape. In this environment he is able to discover ways to offset the disruption his stroke has wrought. James' words also represent a form of biographical work. Through biographical work he is able to develop a new, more flexible, dynamic and artful social construction of himself as a school boy. These clever constructions will also be subject to change as he grows stronger.

Body-reflexive practices . . . are not internal to the individual. They involve social relations and symbolism; they may well involve large-scale institutions. Particular versions of masculinity [and femininity] are constituted in their circuits as meaningful bodies and embodied meanings. Through body-reflexive practices, more than individual lives are formed: A social world is formed (Connell, 1995, p. 64).

The body as examined as a social construct is a relatively new theoretical concern (Faircloth et al., 2004). The individual body has previously been conceptualized as a collective biological form upon which culture plays its endless and varying influences (Armstrong, 2012; Lock, 1993). This turn toward attention being placed on bodily representations is challenging as the body appears increasingly elusive, revealing itself as a fluid, dynamic, and a problematic site appearing to withstand unified theorized portrayals (Lock, 1993; Scheper-Hughes & Lock, 1987). Armstrong (2012) discusses Emile Durkheim's seminal work which was first published in 1912. He outlines Durkheim's suggestion that 'the ideas of time, space, class, cause (and) personality are constructed out of social elements'.

Thus, the body becomes a site for investigation through its reproductions and indoctrinations of social elements (Armstrong, 2012). Although challenging, the examination of the body as a social construct enables an investigations into a dynamic entity with an evolving identity that reveals our present-day society (Armstrong, 2012).

Waskul and Van der Riet (2002) also explore the body within social theory and suggest that the body is both object and subject and functions as a source of ongoing negotiated meanings through a continual relationship between self and society. They extend this notion through the study of chronic illness and explain how a patient is required to re-structure the 'ill' body within a framework of self and social interations. Consequently, the body as a social construct assumes a fundamental position and becomes a site through which the processes of meaning making and identity (re)structuring are constructed (Faircloth et al., 2004). However, what must be taken into account is that these individual processes of meaning making and identity (re)structuring are undertaken from under continual cultural and social moral judgments. This can be seen when a person's body contravenes accepted conventions and norms, and they run the risk of being viewed as wanting or as other. Conversely, when bodies comply with valued and accepted judgments they are upheld as ideals to be strived for. Social judging convinces and coerces individuals to shape their bodies into socially accepted norms (Lorber & Martin, 2000).

Whenever a body is socially constructed it also constitutes a construction of the self as embodied. The socially constructed body thus impacts on not only how a body is represented but also determines how one may live (Synnott, 1992). Social judging is both convincing and coercive, but it can also be seen as illustrative of the values and interconnectedness between culture, sub-culture, and the individual (Lorber & Martin, 2000; Synnott, 1992).

'Im not going to that place for my rehab. That's where all the kids with real problems go. Im not a retard. Il go to the gym and get a personal trainer to help me learn to walk and run properly'.

James' articulations emphasise how biographical work may intersect with the social context. In addition to highlighting the influences and impacts of the socially determined self, his words also align with Gubrium and Holstein (1998) concept of biographical work where James is capable of constructing malleable adaptations towards determining who and what he now is.

The body as object: The body as subject

'It's still my hand. My leg and foot, and shoulder are not right but it's my hand, that's the worst. I was boxing with my friends and didn't look when I put my hand into the boxing glove so I didn't realize my fingers were bent backwards. I think I broke one finger. I just can't feel it'.

It appears from James' description of his problematic post-stroke body that he constructs his body as a separate, passive, and foreign object (Faircloth et al., 2004). The hand needs to be controlled by the mind, as when it is not looked at directly and placed correctly it does not follow the instructions of the mind. This notion upholds a mind body dualism and represents a disconnected and superior mind over a problematic body. However, Merleau-Ponty (1962) calls this Cartesian dualism of mind and body into question. He determines that the body is the embodiment of self. He proposes the centrality of the body and that the self is realised through the body. Thus the body is more than just an object. It is not simply the vessel or residence of self and not just the intermediary between self and our world, but rather the body is representative of self and without this representation we have no self in this world (Merleau-Ponty, 1962). That is, there would be no interactions between self and mind, and self and the social world. Moreover, without these interactions there are no opportunities for growth and development (Corbin, 2003). Therefore the primary site through which the individual comes to know his world is through a body which ambiguously exists as both object and subject (Merleau-Ponty, 1962). This philosophy enables insights into the notion of a continual dialogue from body to mind in the form of bodily sensations, which are layered in meanings. These layered meanings are the body's language, and it is this language that the person learns through an on-going discourse between mind and body and how meaning is derived (Corbin, 2003).

The workable body is an extension on the idea of meaning making through mind and body discourse. This concept suggests that the individual achieves meaning through bodily performances (Faircloth et al., 2004).

'I can't do a lot of things as well as I used to. I've got used to not being one hundred percent. But I'm still very strong, and fast. I mean I re-learnt how to do a backflip at the beach one day. Like I just did it.'

On revisiting James' narratives I realise that he may not be describing his body as an object to be managed whilst he attends to biographical accommodation and biographical work. Rather he is explaining conversations between his self and body (Faircloth et al, 2004). His body is talking to him, and he is listening. Body and mind work together to re-learn and re-develop an emerging new self. The meaning of this on-going reciprocal dialogue between mind and body is derived through self-interpretation (Faircloth et al, 2004). It appears as if James is transforming and adapting to his post stroke body through these biographical performances and with an integration of mind and body (Faircloth et al., 2004; Gubrium & Holstein, 1998). He is reflective and is able to consider what he can, and what he can no longer do. He appears to settle upon a new self. This new self is a more aware self that includes a newfound interconnectedness between mind and body.

'I'm still James, I'm just a more cautious James'.

Repositioning the body through performance

'Searching for and developing markers of continuity with one's former life was a wrenching experience that often resulted in feelings of defeat. Study participants attempted tasks that were beyond limits of what they could do.' (Becker, 1993, p. 153).

Research has indicated that a normal practice widely adopted by stroke survivors is an engagement in existential and experiential testing of the body (Faircloth et al., 2004). Body testing is viewed as a critical component through which the person develops a working understanding of their new and bewildering form. The individual is able to determine benchmarks against which to measure progress. However, how far one pushes this newfound body, and within which context is subject to the individual (Faircloth et al., 2004).

'James backflipped off the wharf', declares his friend with delight. James had gone down to the local beach with his friends earlier that day. It is approximately eight months after his stroke. He is taking a daily dose of warfarin to keep his blood within optimum INR levels as his carotoid artery is still compromised with an unhealed flap. He is struggling significantly with aphasia, crippling fatigue, and right side hemiplegia with the total loss of sensation and fine motor control in his right hand. James is beaming. He explains that he did not quite execute the landing he had hoped for and had hit the water hard on the right hand side of his body. He will be extremely sore for the next few days, but he is victorious.

'I think if I have to list the worst parts of this, it will be first my right arm and hand, not being able to talk, and then the fatigue. But you know for the first few months I had nothing to do but just stayed in bed, so I didn't know I even had fatigue. Fatigue only hit me when I went back to school. I failed NCEA Level 1. But what bothers me the most is my hand. I can't feel a thing and my co-ordination is not good. Even now I have to adapt my workouts as I can't use both hands together. Also I still can't tell if I'm overworking muscles so I have to judge it by looking and feeling the other arm. But I have learnt how to control pressue when I shake hands'.

I use the following four photographs to further illustrate James's engagement in body testing. These photographs were taken approximately one year after his stroke. Photographs are snapshots of captured moments which are frozen in time. However, they show only part of a story (Frank, 2010). These pictures are simply constructs. Nevertheless perhaps the Reader may catch a glimpse of how James challenges his precarious post stroke body with ongoing biographical performances, and experimental and existential testing of his body. The Reader may decide what these photographs really represent.







Coping through immersion in peer group culture

'When your day is long and the night. The night is yours alone. When you're sure you've had enough of this life, well hang on. Don't let yourself go. Everybody cries and everybody hurts sometimes. Everybody hurts. Take comfort in your friends. Everybody hurts. If you feel like you're alone, no, you are not alone.' (Berry, 1992).

James lives with the uncertainty of chronic illness. Since the age of fourteen his life has been significantly disrupted. James lost his voice. He lost his language. He lost a normal life. In line with past research it appears that social support, especially enduring friendships, offer a buffer against the potentially devastating psychological distresses one may face when coming to terms with, and grieving the loss of a 'normal' life (Battles & Wiener, 2002).

'I've always had friends. I just didn't think that anything would change'.

I use the following storied accounts to illustrate the importance of friendships and the vital and, at times, pivotal roles, these friendships played in James' journey toward regaining and reclaiming his self.

I became ill before James' first birthday. He was to be an only child. He grew up in a quiet and still home. But each day the stillness would be shattered by the young voices of the many friends that flocked around him.

I remember back to a time when James has just started his new primary school. He is the new boy. I drop him at the school gates and I watch him run up to a group of boys. He looks so small with his large school bag unstably balancing on his little back. He trips and falls over. The group of boys turn and laugh, and begin kicking him while he lies sprawled on his stomach pinned down by his large bag. He looks like a vulnerable stranded sea turtle. I sit in my car watching, holding my breath and clench the steering wheel. I want to run over to my little boy and pick him up, protect him, and chase away his tormentors. But instead I wait. I watch James as he stands up, and laughingly begins to tackle the other boys. I am amazed. What had seemed like a scene from *The Lord of the Flies* has turned into a jolly group of little lads happily strolling up to their classroom. Some of those boys are still his friends today.

They arrive on the second day of his hospitalisation. I notice them standing at the doorway of the HDU. They are white faced and still. His best friend is there. He stands still and quiet, but I see silent tears falling down his face. He is no longer the cocky cool teen, but a frightened boy. They have waggled school and caught a bus to the city hospital. They had witnessed the fight where James had been 'sucker' punched in the back of his neck. They had seen him collapse the next day at school. I tell them James is very sick. I tell them we don't know what is going to happen. I cry too. They come the next day, and the next. They came, and they never left him.

James comes home after two weeks in the hospital. Each and every day after school his friends would arrive. I remember back to a particular day, about three months after his discharge. They are all sitting in James' room. I hear one of the boys say with glee, 'hey James you sound crazy when you laugh man!' James has lost the quality and pitch of his voice in addition to his aphasia, and he laughs in a high shrill, 'shrieky' tone. 'Hey say sleeping bag'. 'No make him say subway'. As I listen, I remember how my hands had grasped onto the steering of my car and how I had held my breath as I remember that incident in the playground all those years ago. But can he cope with this? His words are so limited now. His speech is slurred and he cannot retrieve or articulate words. He looks over at his

friends and gives a half nonchalant shrug. He manages what sound like ‘whatever’. They clap him on the back. ‘Good you said a word’. They all laugh, and over and above their laughter, I hear that crazy ‘shrieky’ laugh. He is happy.

‘It’s still James he just can’t talk anymore’ - James’ cousin.

‘I think that they were the reason I got my talking back – my friends helped me talking. It wasn’t doing therapy’.

Conclusion

Becker (1997, pg. 39), explains;

‘Both past experiences – including illness, life transitions, and other major events – and expectations for the future inform current experiences of health and illness. People experience illness and impairment from a perspective determined by their historically situated and contextually informed bodies.’

Kaufman (1988, pg. 281) suggests that ‘the way ill persons come to terms with loss or change will greatly determine the meanings they give to the illness’ and that this occurs out of the stroke survivors ordinary everyday performances and practices. It appears that with adolescence their ‘historically situated and contextually informed body’ is one of dynamic movement within developmental growth, and thus is not fixed or complete (Becker, 1997; Erikson, 1970). Perhaps then when James had his stroke he had no preconceived ideas or concrete formulations of his embodied state. Rather, his subsequent biographical performances and everyday practices were shaped without being defined by corporal boundaries, and nor within a fixed context. This may have allowed him the flexibility to be in his illness and disability whilst evolving and moving through spaces of ill and well, at the same time embracing new possibilities and potentialities within his post stroke body and within an accepted interconnectedness of self and others. Although he may be viewed at times as other by some, he is no longer other to himself (Richards, 2012).

One last story

As I write the concluding words of this chapter, James is somewhere high up in the sky over Australia. He sat his final exam completing his first year of university study a few days ago. He is on an aeroplane on his way to Africa where he will be backpacking for the next six and half weeks. He will meet many different people on his travels. He may when he first meets them, slur over a few words. He may be a bit slow with his handshake as he thinks carefully how much or little pressure he needs to exert. He may show a slightly crooked smile when he is tired. But they will not know. All they will see is a healthy strong New Zealand lad backpacking around Africa.

CHAPTER SIX

CONCLUSION

Experiencing Collaborative Autoethnography

All writers, each time they write, work through the tensions and compose a text that can always be otherwise, always be improved, a text that is inevitably only a step, a kind of placeholder, from which still other inquiries with still more field texts may be imagined and pursued. (Clandinin & Connolly, 2000, p. 157).

Carolyn Elis describes autoethnography as ‘dangerous’ (Ellis, 2004). I realize looking back that when I first read those words I did not fully grasp just how dangerous it could be. In the beginning I had lengthy discussions with my Supervisor, unpacking the multiple and complex issues surrounding this work. I had felt ready. However, I held in my hands not only mine but also my son’s story, and the true weight of this began to unfold through the performance of this work. Hollway and Jefferson (2000) talk about the relationship between ambiguous representations and the individual’s experiences. Throughout the writing process this notion became clearer. Moreover, the idea that we find ambiguity difficult to accept and therefore strive to resolve tensions was brought into sharp focus as when it is difficult to find a resolution and to resolve the tension we live in fear that we may never find closure. This hit home particularly hard as a mother of a broken child. James will never have a fully functioning body, he will always have to compensate and negotiate his way through life. From my own experiences of living with my precarious body I can promise you that storytelling from an inbetween space or ‘the frightening no man’s land’ (Kleinman, 1988, p 181) is frightening, and at times dangerous. However, I also came to understand that if my aim was for closure, for resolution and eradicating tensions, I would not have been able to use our stories to develop insights and deeper understandings into living with disability and chronic illness (Richards, 2012). My research process has been one of transformation, and ultimately has resulted in a transformation of a sense of self. That is, something new emerged from the writing, and part of that is a new self (Richards, 2012).

I have struggled with my chronic illness and became unwell and then well again whilst working on this thesis but this will not be evident in the writing. I did not wish to deceive the Reader, however, in order to understand chronic illness it is essential that we

understand how illness and wellness are constructed in mutual relationships as it appears that deconstructing and reconstructing selves may simply result in another ‘thing’ to be analyzed, critiqued and (de)constructed, and therefore are rendered nothing more than again as provisional (Shildrick, 2002).

Through my research I was time and again confronted by the fact that the medical model effectively silences the voices of the chronically ill and/or disabled (Defenbaugh, 2008; Karnilowicz, 2010; Shildrick, 2002). Moreover, social models may also manifest exclusionary ideas as they tend to focus on the individual’s impairments and the resultant unequal social relations between the chronically ill or disabled and those who fulfil the normal healthy socially constructed expectation (Shildrick, 2002). Furthermore, exclusionary practices occur with a focus on the restrictive nature of the disability or a particular illness. These exclusionary models of thought disregard the essential relationship between the embodied subject and their world and the view that our subjectivity involves in a becoming in a world of others (Becker, 1997; Clandinin & Connolly, 2000; Lorber & Martin, 2000; Shildrick, 2002). Although I was aware that it is imperative to hear these previously silenced voices, the question was how. What I have come to know is that chronic illness or disability is not just an issue for the chronically ill, rather it involves us all. The chronically ill person can offer an authentic voice and reveal what it means to live a life with a chronic illness. However, I do acknowledge that through this medium there is a risk of continued separation and ‘othering’ and with a potential splitting of ‘primary and marked embodiment’ (Shildrick, 2002, pg. 64).

Throughout this writing I have been continually confronted by marked dichotomies and the notions of dualisms and binaries. I now believe that it is this very separation of one from the other that may result in a tear from the interconnectedness of humanity and a continued societal ‘buy in’ to what is perceived as either in or out or as one or another. I have found that many studies of disability and/or chronic illness are single authored, with the author identifying as either abled or disabled, chronically ill or healthy, and insider or outsider. There appears little emphasis on the idea that an individual can exist within multiple planes and move between different spaces, and in this instance exist as simultaneously ill and well. Moreover, that the individual can hold dual citizenship, and may speak, and understand the language and be intimately connected to the culture and customs of the very different lands of the ill and well (Richards, 2012; Sontag, 1978).

This was a challenge in itself as I came to know that my research was an ever evolving and dynamic process. I was attempting to capture and tell of a space that is flexible,

fluid and forgiving. A space where bodies are pervious, and like everyone else where we all move and swing between different spaces with no guarantees, no absolutes, and no certainties as we travel on our life's journeys. Autoethnography enabled me to create this inbetween and dynamic space. I was able to explore my feelings and express my ideas from a type of fluid littoral zone (Richards, 2012). Writing through this medium enabled me to extend beyond mere representation as I was able to give meaning to our stories. Although difficult at times, these very challenges enabled me an authentic voice to tell about the multiple and complex states of self. Time and again I was confronted by an inherent desire to resolve these tensions, to give a concrete conclusion neatly enfolded within understandable theory (Richards, 2012; Shildrick, 2002). However life is not neat, it does not run a predictable nor linear pattern with a comfortable ending.

This collaborative autoethnography enabled me to see that living between the worlds of ill and well can offer us a bounty of gifts and a richness of experience in amongst the tear from other, the pain and horror. Moreover, as noted I have come to know that an inbetween state is not static, but is a fluid and dynamic space filled with prospects and potential. I also realised that I cannot offer the Reader a well ordered conclusion to this narrative, as like life, stories are alive and continually move, evolve, and change.

Was it truly autoethnographic?

In comparison to the dominant discourse of the scientific positivist approach, the epistemological principles of reliability, validity, and generalisation are considered from a very different standpoint within autoethnography (Bochner & Ellis, 2002). The tenant of reliability is towards honesty and truthfulness (Denzin, 2009). Reliability and validity are anchored through the narrative being interconnected with life and authenticity is gained through the process of writing the story and seen through a development of meaning and self-awareness within the writer (Ellis & Bochner, 2002). Ellis and Bochner (2002) explain generalisation as being established by the listener as they decide whether the narration 'speaks' to them about their experiences or about the lives of others with similar experiences.

I refer to some of the many researchers and authors who outline specific criteria which should be included in this type of work (Bochner & Ellis, 2002; Chang, 2008; Denzin, 2009). Although these criteria may vary they generally include the following; the

contributions the work has made, whether it is aesthetic, reflexive, what type of impact it has made, and does it truly represent lived experiences.

What is the contribution?

As I explained in the beginning of this thesis, my aim was to construct an alternative paradigm to challenge established and traditional patriarchal epistemologies. I wished to disrupt the long held and powerful assumptions of dualisms, dichotomous thinking, and binaries which communicate exclusionary practices especially within health psychology. This resulted in me having to muddle up womanhood, motherhood, and scientific professionalism in order to debunk the myth of the omnipresent Scientist Researcher, and ensure that my psychological findings are ‘of this world’, inclusionary and relatable.

I also made claims of creating a counter-knowledge. The creation of a counter-knowledge can be seen as an evolving process which came to fruition through the revealing of the narrative. As previously explained narrative rationality is unlike propositional rationality (Goodhall, 2008). It is the transformation of intangible experience into tangible text which showcase insider experiences and knowledge whilst exposing existing tensions and intra-psychic processes occurring within the patient and the apparent gaps between them and the medical field. This counter-knowledge reveals the underbelly of a patient’s experiences whilst highlighting the necessity of this knowledge to be pooled with existing medical knowledge. This new way of knowing or counter-knowledge represents our personal illness storied accounts entwined and confined within the overwhelming statistics of the taken for granted medical narrative. As Murray (2000) explains the generation of a new or counter-knowledge may promote deeper understandings which enhance the development of a reciprocally comprehensible world.

I made clear that I needed to ensure that I engaged with relevant theoretical concepts to ensure that this tale was not just a mother’s lament, but a serious attempt at robust psychological research. Although I presented a single case study and adopted human agency as the unit of analysis I have shown how theory may relate to the individual.

On a personal level this work has contributed to my understanding of living with a chronic illness. Furthermore, it has revealed to me the many complexities which James has faced as an adolescent dealing with disability and chronic illness. Amongst this I came to know about matters I had been previously unaware of. Moreover, I appreciate that through

Comment [KC2]: “theoretical concepts” or may just “theories”? Don’t think you can have theoretical theories!

this collaborative autoethnography I was able to confront the many matters that I was unable to face before. This was particularly important to me as a mother confronting the idea that my child was to be permanently altered and disabled. Looking back I now recognize that this was a thought that has been too distressing and disturbing to contemplate. This hit particularly hard when I finally grasped whilst editing that I had been using speech marks around the word 'disabled' when I wrote James' story. I finally understood that his 'disabledness' was not real and I was trying to convey this to the Reader by indicating a different meaning of the word disabled. I was attempting to express that James was 'disabled' – but not truly disabled. However, I have now accepted that his stroke has left him disabled.

The underlying performances culminating in the production of this thesis has allowed me to challenge these issues in a safe way. It has also enabled me insights into mine and my child's otherness. However, I have also come to know that we can extend beyond binaries and accepted views of dichotomies and 'separateness' and embrace an inbetweenness through an integration of our own otherness, and an interconnectedness with other.

This was not simply a therapeutic journey. It was also a journey of coming to terms with my own 'ill' self through storytelling. In doing this I had to challenge my long buried (mis)perceptions of my illness narrative, whilst I attempted to contextualise James' experiences. This collaborative autoethnography appears to be somewhat unique. It is a story of a mother and child and lived experiences of chronic illness and disability. Moreover, these stories were told within a particular postmodernist and feminist framework. I was able to investigate and contextualise our narratives against this backdrop in order to (de)construct and (re)construct them into clearer perspectives. These perspectives extended beyond dualisms, they promoted the idea of a perviousness between bodies, the embodied subject and other. Furthermore, they provided an alternative view of the possibilities and potentialities of lives interrupted by chronic illness and disability. Therefore this research offers a distinctive perspective; it offers a counter-knowledge, but also a valuable one.

What of aesthetics?

The concept of aesthetic worth and the many different theories surrounding this criterion appear somewhat elusive and subjective. The question is, did I capture these experiences in an emotionally rich way? Did I create thick descriptions which enabled me to reveal to the reader our stories as I invited them in to our unversed world? Did our stories

have verisimilitude? Did they evoke in the listener a feeling that the experiences described were genuine, believable and possible?

The stories I presented brought to the fore our life histories, our lived experiences, and human agency. I embraced a vulnerable and transparent self as I wrote our emotional realities. This enabled me a sense of freedom and an authenticity of voice. I was therefore able to tell our stories bound up within the facts and statistics of a 'medicalised' narrative.

The Reader may note that I did not show much of James' direct voice. That was not our intention, rather we felt his voice was sufficiently conveyed to open the lines of inquiry. If our voices were felt then authenticity cannot be questioned.

Was it reflexive?

In Chapter One I told a story about James in the hospital. The day he tried to escape and climb out the window. I told how I had watched and had not attempted to pull him back, but rather how I knew he needed to feel that he had in some little way succeeded. At the time I did not consciously determine how I should act, I just instinctively felt that it was the right thing to do for him at that time.

However, when I wrote these stories I was compelled to continually reflect upon them. I needed to look back and closely unpack and examine my own perceptions, the metaphors, and the imagery I used. These stories would have been of little academic use without a constant reflection on the unfolding process of writing. Moreover through reflexivity I was able to remain acutely aware of the many ethical issues and safeguard against potential influences within the researcher-mother role, and ultimately determined how I constructed our collaborative autoethnography. Thus I needed to simultaneously scrutinize my memories and look forward into the future to ensure that I truly captured our experiences. Moreover, the aesthetic aspects of this thesis could only be realized as I reflected upon the 'inside' – the very meanings of our experiences.

This constant process of reflection and reflexive practice meant that I was confronted by a tumult of powerful emotions, some of which had been long buried. I was obliged to challenge my own story as I did not want to pollute James' story with my baggage. I came to see that I had never fully focused on my story before. I had avoided it for so long as deep down I was truly afraid. I also came to know that my avoidance has had consequences not only on my story, but on me. Ironically this reflexive process also resulted in a type of

grieving process. After all, in some senses this research was about loss, but this was also a healthy process as it forced me to confront the issues I had avoided for so long.

Moreover, through reflexive practice I remained aware of my compulsion to veer toward more traditional methodologies. I had gone off the path of scientific positivism and had wandered into a previously unexplored methodological territory. I was concerned with the issue of scientific worth. However, I had to remind myself that this research was a deliberate attempt to disrupt the conventional acceptance of what scientific inquiry should be. As I previously noted human agency was the unit of analysis, and our stories were not intended as data for analysis. The documenting of our experiences through storied accounts enabled me insights, understandings, and a type of sensemaking of what had previously been senseless. The act of textualising our insider experiences and finding a space for them to reside gave me a sense of comfort, a sense of belonging through an acceptance of self, and a sense of interconnectedness of other within and other. However, I needed to be continually aware that our stories were not meant as data, but rather they formed the basis of the development and construction of a counter-knowledge. Furthermore, they served as a form of testimony and of giving witness in order to validate our experiences and advocate for ourselves and others.

This continual awareness ensured that I remained critical. It enabled me to contemplate my epistemological uncertainty as I wavered between confidence in my methodology and serious doubt. However, these postmodernist performances enabled me to pose questions, develop deeper insights, and further my thinking and ideas (Richards, 2012). I avoided falling into complacency through reflexive practice. I remained critically aware of how women are historically positioned within a pervasive and accepted dominant discourse. Throughout the production of this work I also remained mindful that reflexivity is a fundamental tenet of feminist research.

Moreover, being reflexive supported me in making sense of the deeply complex, and at times, multifaceted predicaments I found myself in during the process and production of this thesis. Reflexivity helped me to not only make sense of these dilemmas, but paradoxically I was able to accept the imperfect nature of our stories. I also came to accept that as I attempted to structure and demarcate our experiences into coherent form I was unable to always reveal that our narratives were not so much as broken but shattered. I was finally able to grasp that writing in itself is an experience. It goes beyond an attempt at interpretation as it becomes a type of reinvention through structure and form (Lincoln & Denzin, 1998; Richards, 2012).

Did it impact?

Comment [KC3]: All good. This covers the issues you set out to revise.

This collaborative autoethnography had a powerful influence on me. In a sense it has changed me. As I noted above, I have finally fully revealed my own story to myself. I have also been able to accept the truth that my son is permanently disabled. Through writing I have been able to come to terms that a senseless act in a playground left my child paralysed and with no voice. Moreover, this collaborative autoethnography allowed a way to tell our stories whilst managing the deeply nuanced experiences and ambiguity surrounding chronic illness and disability. It led to an understanding that we are more than just occupiers of the binary positions of ill and well.

Does it reveal lived experiences?

Was I able to truly capture our lived experiences? This is a question I was faced with throughout this research. In line with Foucault's (1975; 1991) interpretation of commentary, I wish to make the Reader aware that throughout this work I have been able to make some things visible, but not all as I am aware that I risked rendering some things invisible. I may also have legitimated certain power structures, whilst illegitimizing others, and I may have sanctioned some voices, but I may have inadvertently vetoed others. I do accept that I was unable to reproduce our experiences in their entirety. I was bound by not only time constraints but also the time and space within which this thesis was produced. I am therefore aware that there was much that I had to leave out, although I do believe that our stories do reflect some of the experiences of our interrupted lives. However, the specific time and place in both mine and James' lives effected all meanings of this writing. We are both 'well', and I cannot help but wonder if we were not, how this story may have been different. How would I have shaped these stories if James was still fiercely at war with his demons, or if I still viewed my body as abhorrent?

Future research

My research offers a glimpse into lives interrupted by chronic illness. However, what of those lives who have also been interrupted by chronic illness and disability, but what if their narrative is taboo? There appears a paucity of research into taboo chronic illness or disability narratives. What about the story of the disabled adolescent who drove drunk and crashed his car killing his friends and has been left paralysed? Through my engagement with

the literature there appears to be very few options offered for the chronically ill or disabled. They tend towards the predictable hero, or victim. But what of this teenager? It is probably assumed that he is neither victim, nor hero. What of the adolescent girl who boasts of her sexual conquests and then is tested HIV positive? These taboo narratives emanate from social moral judgments. What spaces would these adolescents occupy? What would their stories be?

A last word

Now that I have finally opened the box and looked inside, I am no longer alarmed or dismayed by my story. I have managed to unpack and dismantle my stories. I have got up close and really looked at them for the first time in nearly twenty years. I am moving towards a settling into, and an acceptance of who I am. I can say that I am no longer afraid of my stories. However, I cannot say that about James. Perhaps this is simply part of being a mother. Perhaps I will always be afraid.

'I know I can't do some things at one hundred per cent – but I'm still pretty good. I mean I don't come first anymore, I like come third.' - James

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