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World Interrupted: An Autoethnographic Exploration into the Rupture of Self and Family Narratives Following the Onset of Chronic Illness and the Death of a Mother

Abstract

Informed by the developments in autoethnography, narrative analysis and biographical sociology this paper seeks to affirm that understanding our narrative enables self-understanding and more importantly enables the understanding of others. Using an autoethnographic approach this paper explores the rupture in self and family identity following two traumatic events: the onset of a chronic illness (Multiple Sclerosis) and the death of a mother. It is the story of the life of my mother, who suffered with MS for 9 years and the story of my sister and myself, who cared for her throughout our childhood up to her death in 2000. The rupture in identity that we suffered interrupted the world in which we lived and exposed the contents of our individual and collective world(s). The themes that emerged from the narratives in this study suggest rupture is experienced as a movement of transgression that leads to movements of regression and progression.

Keywords

Autoethnography; Rupture; Narrative; Identity; Story; Transgression; Regression; Progression

The use of biography, narrative, stories and autoethnography in current sociology notably in the analysis of periods of disruption (Becker 1997) such as illness (Frank 2000; Riessman 1990, 2003; Smith and Sparkes 2005) and grief (Arnason 2000; Gersie 1991; Gilbert 2002; Handsley 2001; Herrmann 2005; Neimayer 2005) has highlighted the importance of understanding disruption by looking at the stories individuals tell about their experiences. By basing their theorising *from* the participant as opposed to *of* the participant, the lean towards a more embodied sociology (Williams and Bendlelow 1998) has given voice to chaotic, non-linear experiences that are primarily *felt* - to suffering that cannot be easily assimilated into a seamless narrative or category (Charmaz 1999, 2004; Frank 2000, 2001).

Narrative analysis reveals how people use metaphors, characterization and emplotment in telling their stories to convey more effectively the essence of people, places, character and emotions (Arnason 2000; Denzin 1989; Riessmann 1990, 1993; Smith and Sparkes 2005; Squire 2005). People connect to personal stories (Ellis and Bochner 1996) by evoking feelings and emotions (Ellis 1999) and thus can

be therapeutic (Gersie 1991) and healing (Rosenthal 2003). They also help the narrator to understand and face trauma (Borawski 2007) and the process of narration can be an emancipatory experience (Wolgemuth and Donohue 2006).

The term “narrative” however refers to many different types of texts. For instance a biography is a form of narrative but is not a narrative in the same way as an autoethnographic account. In the first instance a writer is creating the history of the life of another, and in autobiography, autoethnography and self-narration the writer is creating and inscribing *their own life*. Narrative research does not aim to define the way in which to tell a story or what story to tell. It appears more as a pragmatic politics (Squire 2005). Everyone has a story. This story tells us something about the person and about the society in which they live. It is in this *something* (in this claim to an individual and shared reality) that lies the significance for the social researcher.

Talk of ‘biography’ in social research moreover does not always correspond to the use of biographical methods (Boeije et. al 2001; Richardson, Ong and Sim 2006; Walter 1995). Biography here is the history of a life and the details of an individual’s life are treated as facts. In contrast, autoethnography as a ‘creative non-fiction’ (Ellis and Bochner 1996), sees the author actively moves back and forth between the personal and social using their memory as a resource to allow the reader to enter the experience (Ellis 1999). Autoethnographers are aware that in the act of autobiographical writing it is possible to create different “truths” - versions - of self and experiences (Kehily 1995). The creative aspect of writing is thus embraced and devices from fictional writing and poetry are employed to better capture lived experiences. The truth that is being sought in such research is quite different, as Borawski (2007) recognizes in writing her autoethnographic piece about a traumatic experience:

The memory may limit the details an individual can remember, but trauma is not in the details, it is in the emotion still felt from the event (p. 109)

Narrative research and autoethnography therefore shares commonalities with feminist ethnography in agreeing that there are *alternative* ways of knowing, with rational, quantifiable research methods as only one claim to “truth” (Stanley 1990, Ramazanoglu 1992). If we look at narratives as “factions” (Bury 2001) instead, as simultaneously incorporating both fact and fiction and being transcendent of both terms, we can see that narratives and personal stories are not escapist, but like life itself *social texts* (Denzin 1989:9). As Riessman (2003) identifies, narratives contain both elements of structure and freedom. A narrative is essentially a performance that reveals how we interact and *react* to the structures with we live. The social and historical context frames the narrative.

This paper uses an autoethnographic approach to explore the rupture in self and family identity following two traumatic events: the onset of a chronic illness (Multiple Sclerosis) and the death of a mother. It is the story of the life of my mother Brenda, who suffered with MS for 9 years and the story of my sister Eleanor and myself, who cared for her throughout our childhood. The story continues through to our mother’s death in 2000 at the age of 44. This story seeks to continue my mother’s tale of suffering not only fleshing out the same story with the perspectives of the two other individuals who shared her experiences, but completing it by writing those unwritten chapters, effectively writing an “interpretative biography” (Denzin 1989) of Brenda and Eleanor. The end of one story leads to another as the “audience” becomes “storyteller” (Charmaz 1999). Using data from one family, I seek

to uncover how three individuals experienced a rupture in identity in separate and overlapping ways. By analyzing the transformation – the “interruption” - in the personal and social narrative when experiencing identity loss, this paper explores how a rupture is faced and the consequences - both destructive and affirmative - that result.

World Interrupted

Individual narratives make identity a self-conscious construction; it is not just given but something that is routinely created and sustained in the reflexive activities of the individual (Giddens 1991:52). The way in which a person tells a story can affect the way in which they understand their life and the decisions and actions they make in their life are taken based on this understanding. Understanding our life narrative – our story – helps us to understand ourselves; it brings the past in line with the present and establishes continuity (Charmaz 1999). The importance of maintaining a coherent narrative is highlighted when our self-identity faces disruption. Threats to the continuity of the narrative, most notably death and illness, are sequestered from culture as they remind us of the fragility of the control we have over our lives (Mellor and Shilling 1993). The onset of a chronic illness and the death of a close relative can rupture the secure continuity of our biography and destabilize our constructed self-identity (Frank 2000).

The “rupture” in the title of this paper refers to the rupture in an individual and familial reality. That is, rupture of a perceived sense of normality, a *collectively constructed* normality, not an objective standard of normality. As Bourdieu’s concept of “habitus” (1990 [1980]) describes; we internalise the external world in a selective manner informed by the experiences we have had; the place we grew up, the hobbies we enjoy, the job we do. Each individual possesses an individual habitus that provides “tools” to inform the decisions we make as well as being a resource we continually add to.

A “mythic surround” encloses incurable diseases such as MS that pose an epistemic challenge to the rational order of a society accustomed to a medicine that can cure and explain all (Levin 1987:106,107). Death in itself is not incomprehensible or a “taboo”, the problem lies in the non-existence of accessible languages in which the individual can describe and make sense of their experience (Walter 1994). A plethora of discourses arise to endow meaning and disguise this flaw in modern medicine. Models of a good death circulate, (McNamara 1998) and dying roles (Lawton 2000) and heroic scripts (Seale 1995) are formulated to help the suffering individual objectify and understand themselves, as well as helping others rationalise the “unspeakable” fear the suffering individual embodies. These discourses and scripts of how to act can be greatly influential in informing the way in which individuals tell (or believe they should tell) their narratives (Becker 1997; Smith and Sparkes 2005).

All attempts to express suffering will in a sense fall short because of the lack in language to convey the meaning of suffering (Struhkamp 2005). The narrative written here too is lacking. Giving space to suffering means we have encountered our limits. But letting go of suffering should not be a viable option. To ignore all that which doesn’t fit or resists narrative is to indirectly censor suffering and push it further into silence. Narratives of suffering don’t assume to produce reality “as it was”, but can provide a *viewpoint* on the *experience* of suffering. This narrative viewpoint – “idiom of distress” (Becker 1997: 65) - can illuminate far more to both narrator and audience than silence.

Methods

The central source for this paper is an undergraduate university assignment written by my mother, Brenda Pearce, in 1993 entitled "A life changing event. Coping with disability and the reconstruction of identity following the onset of a chronic illness". The assignment was an autobiographical account in which she detailed the process of reconciliation between her disabled self with her former non-disabled self after the onset of Multiple Sclerosis. To build upon my mothers account I conducted "interviews" - firstly being interviewed myself, then interviewing my sister. I informed Eleanor of the aims of the research and she consented to taking part and allowing this story to be told. She had no objections to the use of her real name.

My preference is to use the term "themed conversation" rather than interview as in each case the interview took the form of a conversation - a mutual sharing of memories and feelings between two intimately related individuals. However by calling them "themed" the constructed nature of the "conversation" is identified. The conversations were arranged with a particular agenda and a number of themes and topics were planned for discussion. The interviews did not strictly adhere to the suggested narrative or biographical interview model (Rosenthal 2003; Riessman 1993) but shared the common principle of narrative and biographical interviews and that is to respect the flow of the individual's narrative.

Before the interview I noted aspects of our lives that I believed acted as a guide. This took the form of a list of themes ordered chronologically. It also acted as a prompt to the friend who interviewed me. The conversations digressed from the loose categories I had noted for discussion but this was expected and encouraged. Eleanor often reacted to remarks and questions in ways I hadn't anticipated, allowing for previously undisclosed emotions to be uncovered. A qualitative interview in whatever form is in many respects an intervention – a situation is enforced that may not have otherwise, or naturally, occurred. Yet intervention can be used as an effective strategy. The narrative interview provides a space for the telling of a concealed story, one that is often long overdue. As Wolgemuth and Donohue (2006) argue, intervention in the form of an "inquiry of discomfort" can be emancipatory and transformative for the participant. An 'inquiry of discomfort' entails creating ambiguity in the identity of the participant in order for them to see themselves differently. An interactive interview aids the participant in dislodging themselves from their comfort zone to explore and tackle traumatic issues. Ensuring that both participant and researcher alike are aware of the transformative and discomforting effects of the narrative interview and the risks involved, the narrative interview should be allowed a certain flexibility to be conducted on the terms appropriate to its aims. It has been acknowledged specifically by feminist researchers that in interviews the influences of factors such as gender are of assistance when actively acknowledged rather than ignored (Ramazangolu 1992; Stanley 1990; Stanley and Wise 1983).

I found initially that Eleanor held preconceptions of an "interview" and of what constitutes a life story which acted to inhibit and regulate her response to something she felt was appropriate. She felt nervous about the interview and about transgressing the boundaries of time and space that are commonly associated with an interview. I realized that I would have to accept these structures and use them in order to deconstruct the issues most significant to her. As Eleanor moved away from

relying on these familiar structures she began to speak quicker and without restraint. In this stream of talk the most salient and emotionally significant experiences were revealed.

In both incidences I tape-recorded the interviews. I listened to the recording the day after to immediately gain a sense of the narrative that was beginning to emerge. My own interview provoked forgotten memories in me, highlighting areas of ambiguity and questions, which I felt I should include when I interviewed Eleanor. I transcribed both interviews which helped to connect further with the emerging themes, as well as noticing those comments that in conversation I ignored, but through transcription drew my attention. I read the transcripts and with my mother's essay through multiple times, and I started to make connections and identify common themes. I compared the loss of grief with the loss of illness. I began to identify individual narratives and a collective family narrative. I wrote down themes and began to group them into "thoughts" or "feelings" "states" or "processes" in order to unpack their meanings. I continued this process using diagrams to represent what the words were trying to say to me.

Throughout this exploration I was informed by the method Plummer (2001) advocates in using 'documents of life' to provide deeper understanding of lived experiences. I looked through photo albums and put the words of my mother behind her face in photos. I looked at how our family transformed, how certain people stopped appearing, how birthdays weren't photo worthy after I reached the age of twelve. I saw places and events I had forgotten, I saw the reality of my past distilled and contrasted it with the past I actively remember. Inspiration came from many different sources. The scent of a perfume, a TV programme we used to watch, birthday cards, birthday gifts, a notebook of my mother's, where we used to live, places we used to go, the antique doll Eleanor has in her bedroom. An important additional source was the journals I have kept over the years since adolescence which acted as "fieldnotes" and a powerful and effective means to 'emotionally recall' on my past experiences (Ellis 1999).

I began writing the story by copying and pasting segments of text from my mother's essay and from the interview transcripts and placing them together to see the three different voices and how they merged and diverged from one another. The order was loosely chronological but events also took place aside one another and some events had impacts that lasted on through to the final stages of the story. Using these voices as a base I began to write in and around to fill the gaps and tie them together. Starting the writing process in this way helped me to respect the order of the narrative as it was shaped by the three individuals in the story. I also gave Eleanor a copy of the finished story and analysis to gather her thoughts and reaffirm the accuracy of the way I retold events.

My proximity to the text forced me labour every sentence I wrote and constantly question myself. Had I actually experienced the feelings in the way I described them or was I just performing an identity I thought appropriate and that fulfilled my preconceived notions of what others expected from me? I felt an incredible responsibility to live by the words I wrote else I would be guilty of creating a false biography and of giving false hope. It was then I directly felt the authority words hold and my obligation to act responsibly. I was left to ponder - does one really become the stories one tells? (Denzin 1989:81) These questions are questions for which I have not yet the answers. These gaps in my knowledge are the freedom within the more concrete words that keep the text open to interpretation. Though I have

'authored' this narrative, it is now beyond me, beyond the individuals in the story. It is text, it is structure but it is also emotion, suffering and pain. This suffering was never really mine to own and it transcends and resonates far beyond the words on this page.

Communicating the Story

I have not titled this section as the "findings" as this label implies that this data was "found" and subsequently that it is the possession of the one who found it – the researcher. This research was not found nor can it ever be found. It is not the aim to tell the entire story or to relay an accurate tale of events. It is communicated here as it was and is, experienced – whether that is through conversation, interaction or the silent moments in between. This story belongs to no one but exists only because it is shared through memories and felt through suffering.

By the time of my own birth on 13th March 1985, my parents were informally separated. In 1979 at the age of 23 my mother Brenda got married in Australia, where she grew up after the emigration of her family in her early adolescence. After my birth my father returned to his native Australia whilst Brenda filed for divorce. Neither Eleanor nor I have any memories of our father. Brenda received custody and ownership of the house that would become our family home for the next 15 years. By the end of the divorce proceedings that were hindered by my father's absence in court and the necessary international transactions, he had remarried and Brenda had been diagnosed with Multiple Sclerosis.

In 1988 Brenda began to experience difficulty in walking, a stumbling that was noticeable for someone as fit and agile as herself. Brenda was looking to return to her job as a librarian once I started school. When I did actually start school, my mother was free to work but by this time, she was unable to walk. For four years Brenda was in a limbo of no diagnosis, fighting to remain "normal" yet suffering from continual falls and imbalance. Brenda remained active in the face of her diagnosis and deteriorating health; she worked voluntarily with people with learning disabilities, she got involved with the local church, creating great flower arrangements and seasonal banners. We went on days out all around the country and had a holiday every year. Eleanor and I both attended ballet and tap classes from the age of five. Every year we both had great birthday parties and always the crowning feature – an immaculate homemade birthday cake. Brenda furnished the house with antique wooden furniture and endless ornaments that she bought cheaply and restored. She decorated the house with numerous hand stitched embroideries and cushions and framed pictures. She made a magnificent patchwork quilt for Eleanor's bed and a wall hanging in my bedroom. The house always had certain grandeur about it, a sophistication that exemplified my mother's taste.

Childhood was a peaceful and contented time for both Eleanor and myself. For either of us to detail the time when things changed or worsened is impossible. It happened so *gradually*. If you look at it plainly it was only 9 years – in which a perfectly able sociable being disintegrated, lost control of all bodily functions, became wheelchair bound, house bound, dependent, socially dead – but this would be to extricate any semblance of the actuality of the experience. I suppose you could look at the number of mechanical equipment and how they increased as Brenda's ability decreased. A stair lift gave way to a through floor lift, the fourth bedroom converted into a bathroom with wheel-in accessible shower and wheel-over bidet toilet. From Eleanor and I physically lifting our mum out of bed, to lifting her out with a hoist and

various straps. Perhaps if we look at how the routine lengthened and deepened, how it seemed we had we had always woken up at 5.45am to get our mum out of bed. How life at home began to encroach on our outside world. How home became a world of structure and routine. Brenda had always been a house-proud person but as her ability to complete even simple tasks diminished she took control by regulating a very particular household regime. Basic tasks took such a long time. We had carers at morning and night but our mum would specify Eleanor to do certain tasks. These ranged for the small to the strenuous. We took care of all the cleaning in the home. Everything was allocated a specific name “windows and pictures” “dusting the sideboards” and everything was done in order, always on the allocated day and time.

We could trace the illness trajectory through the structure of education. Examining the dramatic difference that occurred over Eleanor’s five years at secondary school. At the start, in 1993, our mother had just enrolled at university studying Psychology and Sociology part time. Studying brought a great deal of independence to Brenda as she travelled to and from the campus several times a week, widening her social contacts and learning of ideas that helped her understand her situation. By the time Eleanor had finished her GCSEs, Brenda’s capacity to keep up with the workload and attend lectures had however, greatly weakened, and the studies that had given her so much autonomy and broadening of perspective she had to leave incomplete.

Or perhaps the change happened when I realized it had changed. How I had to pretend - simulate a normality - when I had to write “My Day” in a year 7 German class, in comparison to my ignorance when writing my year 5 ‘weekend diary’ in which I wrote “On Saturday I helped my mum go to the toilet...” Or perhaps it was when we *all* noticed how *other people* recognized change in us. We attended the Sunday service at our local church every week but one particular morning reminded us of our change. We hadn’t been in church long, that morning, when Brenda started to have problems keeping her head raised. We used a form of neck brace ever since she could no longer hold her head up, but it was an unsightly uncomfortable thing that we only used when we went out. I found myself having to hold her head with my hands even with the neck brace, which began to elicit a few stares. A hymn started and she seemed as though she was trying to say something, but because her voice was weak I couldn’t hear over the hymn. I wasn’t sure if she was just crying as she started to get more upset. I was getting frustrated. We were already making a scene, sat at the front of the church as we always did, my hand on top of my mothers head, listening in, asking her “What is it? What is it?” my mother crying, distraught now, tears falling, saliva seeping, anguish on her face. I hear it this time; her broken cry tells me “I want to go home”. And so we had to leave. Down the aisle that had never seemed so long. Eleanor pushing the chair, my mother’s head stooped and limp, me shuffling alongside. The three of us just wanting to get out; out, away from the humiliation, the false sympathy, the stares, the looks that just stand there and say “what a pity”, “what a shame”, “what a shame on a day like today”, “what a shame on Christmas day.”

We could compare how people stopped coming round, how my mother stopped being invited, how having guests was too much strain. How social activities reduced. When Brenda left her role as Sunday school teacher, how Eleanor dropped out of college. We could compare how we were referred to; my mother increasingly as a baby with no opinion, Eleanor and I as ‘poor girls’ or told ‘You’re so brave!’. We could compare before and after we found out our father died. How Brenda coped with truly being a single mother, with the naïve hope of her husband returning completely

destroyed. How to keep faith in her religion, how to maintain a brave face. Compare her independence with the need for someone's presence 24 hours a day, how a couple of hours became unbearable, compare the sociable with the isolation, compare distances travelled, growing up in Australia, holidays abroad, to a trip to the local supermarket bare metres away.

Change is interweaved into all these aspects but there are always the anomalies. Comparison doesn't convey how Brenda was a Derby County season ticket holder, how she attended all the matches, how she was involved in the disabled supporters group. How she frequented the cinema and to the theatre, how we always went to the Christmas Pantomime. How Brenda always retained her elegance and ladylike vanity. How she was remembered for her appearance even at her funeral. Whether or not we were going anywhere her whole ensemble - clothes, jewellery and make-up - would be orchestrated down to the choice of perfume.

Comparisons neglect her sense of humour. How we enjoyed our holidays, how we could still laugh, and how we did laugh, how that laughter equaled the tears. They forget the achievements, how Brenda was awarded her degree in 2000.

Final comparisons: comparing hospital experiences. Compare how she went in came out during the majority of our childhood. Compare how she went in January 2000 and came back home after three weeks. Compare how she was admitted in November of the same year with Crohn's related bowel problems and in four weeks she was dead. But it doesn't compare. The pattern is broken.

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Our mother's death was entirely unforeseen. Neither Eleanor nor myself knew anything about her condition nor did we expect anything other than her return at Christmas. Opening our mother's presents we had bought ourselves on Christmas day was a rather depressing procedure that no one expects or would wish to do. Looking back, the day appears as a badly acted stage performance. Eleanor was called from work; I got called out of class, taken to the hospital, both told we should be there. The other characters appeared to have been informed of their motivations but Eleanor and I were thrown in, told to play along but with no knowledge of the plot – *why* we had to go to the hospital, *why* now? When I see my mother she is as she had been many times before. Eyes closed, oblivious to the world, oxygen mask on. We are told to sit down, one each side, curtain is pulled round. Still clueless about the plot we're off one stage and on to another. We make up our own script, one we think is appropriate. We hold our mother's motionless hands. We have no lines, no directions; we wait for a prompt. When she stopped breathing I remember the shock on Eleanor's face. I remember how the silence broke with the sound of our cries. I remembered all the things I didn't say.

The rest of the cast returned on stage before I could understand the hideous plot that had unraveled before me. Nurses ushered us out. The stages switched, outside the curtain felt like a circus as the other patients stared at us. Even they knew. The nurses finished straightening our mother in the bed. A gap in the curtain betrayed what lay beyond, 'I don't think you should go in girls...' But I had already seen, I had already seen the awkward lifeless body of my mother, her head raised back and her mouth hanging obscurely. The corpse of my mother – the image spun in my head and haunted me continuously in dreams.

We were ushered along to a friend's house but the morose formal mood was too much. We just wanted to be home. Yet when we did go home we were not left in

peace as people came around in floods offering their sympathies. Eleanor and I feigned the appropriate niceties. It occurred to me that my mother wouldn't be at my 16th birthday. I thought of all the things that would never happen anymore. Eleanor and I allowed ourselves to be guided through all the funeral details. The funeral I remember standing and not crying. The same church aisle that we had been stared at for so many years, we were stared at for the final time.

After a two-week period and a charade of a Christmas we were exposed to the world that demanded obligations from us. For the past year Eleanor had dedicated her life to being a carer. She had dropped out of college, she had no A-Levels, no university plans. She wanted to escape and try to find a new life. Eleanor moved away about four months later under the persuasion of her first relationship and the allure of something resembling a life. She started to work, which began to reduce her feeling of isolation. The new life she entered felt foreign but it opened her eyes to the bubble in which we had lived all of our lives.

I returned back to school to receive initial welcoming from teachers and the silent treatment from peers. It wasn't long until I started to skip lessons, tactically making my way unnoticed through the school gates simply to go home.

I lived alone in the house that held the memories of my lifetime and of my mother. Her room I left untouched entering only to smell the musty unchanged air and cry for my loss. The house became the container for my grief, my memories, my eating disorder. Two years later when I moved out and we sold the house all my anxieties, panic and fear spilled out onto the world.

Discussion

The discussion that follows aims to open the narrative and make wider connections to sociological research as a whole. A distinction should be made between making sense of a narrative, which retains a proximity to the subjective understanding of the experience and of categorising experiences, where individual understanding is often lost or subdued. Three general themes – *transgression*, *regression* and *progression* – are introduced to help illustrate that transition is not simply individuals moving from one place to another but that it is crucially affected by the *significant others* around them, the *space* they inhabit and *meanings* they embody in them. The themes are not simply a way to theorize the description but reflect the movements of the three narrative accounts. The themes are not fixed but possess a certain flexibility that conveys how the three narratives interweave with one another.

Transgression

I had now acquired another label, that of disabled, which I had imagined would make me feel and act differently; instead I felt the same...*Brenda*

Transgression is the name given to the process when an individual conducts some error; they lapse or fault in their performance. In effect to "transgress" is to be accorded a "spoiled identity" (Goffman 1968). The extent to which we transgress into the role of "other" depends on the role given to us by others and how we react to that role. Those who experience loss and disability were once "normal" and now become the "other" they are ill equipped to deal with. This initially brings a great deal of

ambivalence. The other is realised within ourselves and we are no longer able to demarcate the other as an external entity. We instead demarcate our own biography in terms of “before” and “after”. The past requires reinterpretation in order to make a plausible and coherent biography and to make sense of our transgression (Berger and Luckmann 1971:178). This process of reinterpretation is all the more profound in the case of grief and chronic illness due to their irreversible nature and the fact that we comprehend our reality in opposition to the uncontrollable chaos that the two incidences pose. Grief and illness not only force the individual to transgress unwilling into the role of other but they do so by undermining everything that the individual assumed as reality.

My mother found her self assigned the role of disabled but could not understand why she felt the same. She already had preconceptions of what ‘disabled’ meant.

From being what I perceived as a useful member of society, I became an unwilling member of a disabled culture, of which I knew nothing and whose members I had always viewed with sympathy and saw as a burden to society

Able-bodied = useful, *disabled* = figures of sympathy, a burden. These preconceptions had to be altered now that she was herself on the other side of the margin, now that she had *transgressed*. Chronic illness reorganised action in Brenda’s world and how she experience time and space (Leder 1990:73). The landscape of her world was transformed from a field of opportunities into a field of difficulties to negotiate (1990:81). Brenda was confronted with her own body and with her own deficiencies. Her body “dys-appeared” (Leder 1990). That is to say, the “dys”, ill or bad, features were made prominent. The biological dysfunction of the disabled body led to social dys-appearance. The challenge of disability was not simply a physical but a social rupture. Its *irrevocable* nature meant she had to re-interpret the “other”, which she had distinguished herself from. Brenda found she had no idea how to act as a disabled person and so she foraged for an identity, searching for her lost self, refusing the stereotype of disabled. There were no adequate scripts to follow that depicted how she *felt*. This process of emulating a new lifestyle or maintaining the one she knew was stimulated by the fact others reacted to her differently.

I realised others perceived me in a different way and their treatment of me began to influence my actions

Maintaining our expressions is vital as a “minor mishap” can lead to the image that we foster being “discredited” by the significant others around us (Goffman 1969). A failed performance on the front stage exposes the discrepancy between the front and back regions of our lives. Brenda would alter her behaviour patterns depending on the social setting – the region – she found herself. She could create the idealised version of herself, the one “strong and in control” or act dependent and expect assistance and regard for her disability. Brenda would thus oscillate between embracing the role; becoming a performer on the front stage, a hero in her own life; and shying away, uncomfortable with the role, preferring the role of audience, retreating to the backstage (Yoshida 1993). Having a social meaning was not reliant on merely “being” but on how she would *act* and *appear*. The fact that my mother felt the same - *she was the same person* - presents how no one is inherently “other” or “socially excluded” or indeed “normal”.

Applying for a place at university granted Brenda with a sense of normality. This normality was however only a “phantom normality” gained through a “phantom

acceptance” (Goffman 1968) that was given by others as she attempted to play down her abnormal attributes and play at being normal. This normality and acceptance was far more fragile and prone to being *discredited*. Her identity was no longer credible – for herself and others – as she had unearthed the meaninglessness that lied beneath its masking veneer. As beliefs crumble, as the world is “derealized”, that part of the self that believed in the essence of things dissolves (Parkes 1998:98). When my mother died I lost the life I had but also the life I would have had, and without either past or future to contextualise myself the present stood in to substitute my whole narrative. “I am the person whose mum died” is the label that undermined and obliterated all previous labels of who I was – “I am the girl who looks after her mum”.

The new label was however difficult to negotiate. Our mother’s death also meant the death of my and Eleanor’s purpose in life. The cocoon we lived in was emptied of our old routine; time had no referent; everything appeared non-sensical.

I just really didn’t know what to do ... cos like for a year or so my main role in life had just been like caring for my mum, its not like I was at school or uni or anything like that... I hadn’t really got any A-Levels to speak of so...I just didn’t know what to do with myself. (*Eleanor*)

The negotiating and organising processes of family life provided the main source of “ontological security” (Giddens 1991) by establishing a sense of normality that was the “pivot” upon which we comprehended our world (Gregory 2005). Through “family meaning making” (Nadeau 1998) meaning belonged not to one individual but was held within the space of the family. When our mother died that intricate fabric of meaning was torn. Like our mother 9 years earlier, we were between two worlds, not knowing how to act, knowing we had to go forward but not knowing how. Ahead of us was the unknown – the feared chaos - behind us was the familiar that had given us stability.

Regression

The role we perform has to appear favourable to us; it has to correspond with how we feel and it has to cohere with our biography. The ill effects of an unwanted and *forced* role that *spoils* our identity can initially produce ambivalence but the new label can start to *overwhelm*. In the case of my mother her ambivalent reaction to her disability at first propelled her to take action and get on with life. Yet as her disease progressed and increased her liability for failed performances, she was continually confronted her with her inabilities. As she dropped out of university, as she reduced her social activities, she regressed from the front stage, to the back region that would provide security and familiarity. Our home became the spatial boundary within which Brenda could exert agency and establish regularity, in controlling the cleaning and appearance of her home. She could maintain the appearance of her body, keeping it contained when it consistently transgressed. The house, and the wheelchair she sat in, acted by confining her increasingly “unbounded” body (Lawton 2000).

As a family we worked as a “team” (Goffman 1969 [1959]) to continually contain the transgressive behaviours of our mother and maintain the impressions we gave. The incident at church on Christmas day presents how I tried to limit the ill effects of my mother’s unboundedness by acting as an extension to her body. Our mother could only function with my and Eleanor’s assistance. As Gregory (2005) and Richardson and Ong (2007) discovered in their studies of chronic illness within a

family setting; the complications of family life are illuminated by the existence of a chronic illness, just as the family context exaggerates the complexities of pain. When our performance failed we “dys-appeared” and retreated back to the house that contained the stigma we couldn’t hide. Our “corporeal unit” (Lawton 2000) enabled my mother to continue a social role. In order to complete her university assignments Brenda would record her essays by dictaphone, and Eleanor and I would act as the hands that wrote, typed and perfected her voice. Our agency was situated not within any individual but held collectively; our social activities were *team* efforts.

Working as a unit required a very inward perspective. Eleanor and I looked towards our mother, as others outside looked in on us. As we were pushed out from the spaces outside our safe boundaries, the space between ourselves reduced. Within our false boundaries was similarly a false sense of time. The encompassing nature of the routine distracted us from realizing that its purpose was to merely grasp at control, to provide desperately needed *ontological security*. When our mum died and the integral piece of our team was lost, the unreality of our world was compounded to us.

I felt really empty and numb for ages, I didn’t – so like empty, so like not even there. (*Eleanor*)

This unreality Brenda had already been facing. As she became increasingly confined to the house, a couple of hours would leave her distressed. The absence of company, the absence of purpose, mirrored her own deficiencies, her own absence. This unreality overwhelmed like an abyss. An abyss never ends, there is no concept of time, it removes you from what you know, it erases your past. The label was the only meaning Brenda possessed and it became all that she was.

After my mother died the unreality of my world was brutally revealed to me and yet I could not align myself with the normality of the outside world I had craved so long. Living alone perpetuated the sense of living in a faceless abyss. School gave a little sense of routine but I soon rejected the rules and roles they offered. The evasiveness of pain that is felt in grief summons the individual to a continual present where a future cannot be envisioned and the “painless past” seems impossible to recollect (Leder 1990: 75,76). This places the individual in a form of “temporal inertia” (Lawton 2000). Loss of meaningful time and restricted space work together in producing a gradual disintegration of the self (Lawton 2000). I retreated back to my cocoon; to the house that no longer contained the unit I belonged to, but contained my floundering piece. When the unit broke, Eleanor and I both became missing pieces. Without our mum we didn’t really fit together.

A critical moment, such as maternal loss, can cause far more rupture to the protective cocoon in this unstable state, where the identity is still under construction, than at other stages in the life narrative as it easily destroys the assumptive world (Thomson et. al 2002; Hurd 1999). The past becomes harder to reconcile with the present, as both are equally undefined. The before and after division in the narrative thus becomes far more profound (Schultz 2007). Nonetheless, the critical moment can provide an opportunity for the young person to radically change their identity and exchange the life they knew for another.

Progression

Boredom is the dream bird that hatches the egg of experience (Benjamin 1973 [1936]: 91)

Progression entails forward movement, advancement, but often is used interchangeably with an emphatic optimism; implying progression only happens if it is perceived as positive. As Benjamin observes, boredom – the threat of meaninglessness (Barbalet 1999) – is necessary in “hatching” new experiences. Progression occurs when the individual realises life is about *more*. My mother managed to progress by accepting her label so that she was not only the person with MS but also the university student, active Christian, voluntary worker etc. As life expanded, the future and past opened up and began to cohere.

I came to realise that in order to gain control over my life, I needed to combine aspects of an able-bodied identity with those of a disabled self to create a new identity. (*Brenda*)

The connection with the label of “other” becomes part but not the total of the self. The *foreign* is integrated into the *familiar*.

By losing her mother at 18 Eleanor found progression was forced upon her, she had to mature rapidly in order to adapt to the situation she was now faced. Because of her age she was in a crucial phase where she had the opportunity to create a new life and to build upon and test her relatively established sense of identity. Her identity as carer was redundant with no one to care for and so she spent a period of time working different jobs. Earning a wage for a day’s work gave her a sense of pride and achievement. As she regressed from the front stage that was her life and the community where she had grown up she became part of a group that didn’t know her past - her *stigma* - and she could create a new version of herself. To truly progress however she had to *confront* her loss and *reinterpret* it as the inspiration for her future. By starting a nursing course in 2003 she managed to maintain her identity as carer by redirecting its focus. The memory of her mother became the impetus for her motivation. As Stroebe and Schut (2005) identified, it is necessary to relinquish certain bonds (role of carer for example) whilst continuing others. The continued bonds however often require relocating or transforming to make sense within a changed reality. The role of daughter could be continued by reinterpreting the daughter role and relocating the mother to a different place in ones life, but nonetheless a place where it is still possible to continue the bond through remembrance and conversation, as in the terms Walter (1995) describes.

The connection with the “other” within us remains ambivalent. Its face hides or reveals itself depending on the situation. After a university lecture on MS Eleanor found herself going back home later in the day to cry and release her emotions. Talk of death and situations that confront us with the memory of loss – Mothers day, anniversary of her death, other people with MS – temporarily overwhelm but the newer aspects of our identity fight back. That area of ourselves - the memories of a past life - have to be relocated. This allows us to select the appropriate memory to suit our mood and situation. Some memories are necessary to remember as they spur us on to progress, Eleanor’s experience of hospitals motivated her to improve practice by becoming a nurse. The memories I have retained are my motivation for writing this study. Memories diffuse and weave into all action, choices, and have built our character.

Eleanor keeps the appearance of her dressing table and places importance on presenting herself just as her mother did. Our habits become an homage to her

memory by keeping her spirit alive but also by literally becoming a part of our self. During regressive stages that bond is lost, we have no linkage to anything. The loss of our mother in our adult life and the loss of having an adult relationship with our mother has meant that we have embodied our mother's identity with our own. She lives on through us, remaining a significance influence on our life choices. The loss is emphasised when thinking of milestone life events such as weddings and graduations or when having a baby but as we grow and become women our bond continues, as we understand her more as a woman. In some ways the bond we have now is stronger because it relies on more than merely being a team that physically supports. Eleanor and I have formed a strong bond that we never had when our mother was alive. By both of us "conversationally remembering" we have recreated, in a new form, the corporeal unit in which we had always existed. Our progression has only occurred because it is deeply entrenched in our past.

Conclusion

I think that life is – like all of the universe – a question of equilibrium
(Sampedro 1996:216)

Through life it is inevitable to some extent that our view on things will gather more dimensions, as we learn new bits of information, take up new skills and add more facets to our personality. Some ideas are swiftly dispelled, but more fundamental principles such as how we react to and interact with others and our environment remain consistent. Our externality is variable, our character constant. *Habitus* helps to explain this by highlighting the tools that are already in our make-up. Their availability to us and our ability to construct a reflexive narrative depends on the experiences of our lives. No one singular incident can be highlighted as the cause of one reaction, because this simply throws up more anomalies and questions - why do some people adapt? Why do some people succumb? These are the wrong questions.

Reconciliation can be a misleading concept when viewed as an ends rather than a means to progression. Reconciliation is a temporary state experienced when there is *equilibrium* between the front and back regions, the past and present phases of our lives. The past does not overwhelm the present and our assumptions are reaffirmed and feel secure. We feel natural and can just 'be ourselves'. This equilibrium is unbalanced when situations face us with our deficiencies (our mortality) and we *dys-appear*. This confrontation gives us the opportunity to either dys-appear or retreat from the role or to remain resilient and challenge it. The extent to which we can remain resilient in the face of our weakness depends on our habitus - how often we have experienced such confrontation, what grief work we have undertaken in confronting our loss.

This process can be viewed in a linear trajectory but we experience it as we experience our lives, in a cyclical fashion. Yet we are still *moving* though it does not always feel like progression often it is a movement of regression. We are constantly growing and this growth is interspersed with feelings of equilibrium (reconciliation) and limbo (disorientation). The two require constant readdressing in order to avoid transgression. A sense of security can help anchor us to a social structure. This anchor for Eleanor has come in the form of studying nursing and giving herself

direction, creating a new home and having a committed relationship. For me I have been welcomed into a new family that have given me a place in the world, and by learning that has provided me with a sense of worth. It is apparent that it is how we view time and the future ahead that affects how we will act within it. Whether a year or half an hour they can appear unsettling or comforting, but finding equilibrium in our life and our biography reduces the threat of transgression.

Constructing a narrative of my life and of my family's life enabled me to claim my life, for better or for worse. I had to tackle with certain problematic narratives and integrate them into my ongoing life and the constant process of renegotiating my self-identity. 'Problematic' is a general description but 'problematic' glosses critical questions at the heart of my narrative; some are questions: *why did I not overcome my eating problems?* Others are regrets: *I never really knew my mother* or doubts: *I am not competent enough to write this story*. These narratives are more subtle than the clear "rupturing" of a biography, they are more ambiguous, irrational and resistant to assimilation. When we feel in a state of equilibrium these narratives are less dominant and so the narrative we tell is one of acceptance, one of hope (Smith and Sparkes 2005). When in a state of disorientation the regressive narratives overwhelm and we tell a narrative of chaos, instability and incomprehension. These temporary narratives are physical and mental feelings that have been represented in tangible form in the narrative of "rupture" I have shared. These narratives live side by side on another, at times crashing against one another, at others subsiding to an equilibrium.

One final aspect I have neglected to mention explicitly, though I feel it underlies all the ideas considered, and that is the importance of *freedom* in identity. Freedom is a questionable concept – freedom according to whom, how to measure it – but it is clear that by speaking of that which obstructs identity (others, sequestered ideals, meaninglessness, categorising) the heart of what constructs identity is the freedom to be whatever one chooses and the freedom one feels in that identity. Rupture can reveal the *reflexive* nature of identity and how it is possible to live two completely different lives within one. By being reflexive in our approach we can open ourselves up to new narratives – narratives of hope and progression – by posing the question in a different way. The question is not "What have I become?" it is finding "Who do take myself to be?" (Rose 2007).

The rupture in identity experienced by the three individuals in this study allowed a sense of autonomy to be found by attending to self-identity and actively searching for a "voice". As my mother did 12 years ago, I am voicing my narrative – a narrative that is inextricably interweaved with the narrative of my sister and mother – and through *finding a voice*, I am one step closer to bringing coherence and equilibrium to my biography. Though my identity ruptured, *I did not*. Though my world was interrupted *it did not end*. Freedom will always be obstructed by others, threatened by ambiguity and the unknown; the key is to realise that freedom is only given by the self. It is the knowledge that even when you have lost everything, you have not lost yourself.

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