

During Dark Times: Exploring Shame Experiences For Workers with Multiple Sclerosis (MS) – A Creative Non-Fiction Case Study

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ABSTRACT

These are dark times for Australians with disability: Labour force participation rates for people with disability are just 53% (compared to 81% for able bodied), and declining; people with disability who work earn around half those without disability; access to the Australian Disability Support Pension (DSP) is being restricted; and, most disturbingly, around 45% of Australians with disability are currently living near or below the poverty line (Bennett, 2011). This paper presents a creative non-fiction case study of the Shame Experiences for workers with Multiple Sclerosis (MS). Shame is a powerful social emotion and is demonstrated here to be at the root of much suffering, and potentially contributing to people with disability leaving work prematurely.

Keywords: Qualitative Research; Disability; Employment; Multiple Sclerosis (MS); Shame.

DARK TIMES FOR AUSTRALIANS WITH DISABILITY

Disability and lower socio-economic status go hand-in-hand (AIHW, 2010: 254); people with disability experience profound levels of disadvantage leading to higher levels of poverty, social exclusion, and dependence on social security (Hyde, 1996; Oliver, 1990, 1983). People with disability are disproportionately disadvantaged in the labour market and these disadvantages are not simply due to individual functional limitations (Barnes, 1999; Barnes and Mercer, 2003, 2005; Berthoud, 2008). Unemployed people with disability also have poorer physical health, increased mortality rates, and increased mental health problems such as anxiety and depression (AIHW, 2010: 257). While this ugly situation has attracted the attention of policy makers worldwide, with responses including care and social welfare programs, employment based programs, and legislative initiatives (Barnes and Mercer, 2005), current policy initiatives designed to support people with disability have been, at best, disappointing, even serving to reinforce for some their sense of segregation (Barnes and Mercer, 2005). In Australia, this is an urgent problem: around 20% of the population (3,958,300) have a disability -- a proportion set to increase as the population ages (OECD, 2009, 2010).

Labour force participation rates for Australians with disability are just 53.2% (compared to 81% for able-bodied people) (ABS, 2003) and the employment rate for working-age people with disability in

Australia has *declined* since the mid-1990s and -2000s (OECD, 2009), despite policy initiatives intended to assist. As a result, Australia is ranked very low among the OECD – 21st out of 29 countries (Bennett, 2011; OECD, 2010) – and is still declining. And yet there is clear evidence that people with disability want to work: what most unemployed people with disability lack is not ability, but opportunity (National People with Disability and Carer Council, 2009: 30). The purpose of this paper is to: (1) Share a novel qualitative methodological approach; (2) Interrogate Shame Experiences for workers with MS; and (3) Offer evidence that Shame Experiences for workers with MS are potentially responsible for their unnecessary suffering, and premature withdrawal from work.

SHAME, DISABILITY AND WORK

There remains insufficient attention directed to shame experiences in organisational life, especially for workers with disability¹, including those with MS. Having a disability draws intense scrutiny, as well as disrupting lives and eliciting negative responses from those looking on (Charmaz, 2008). And it is not just that people with disability feel different (less) when compared to others; they feel this devaluation, this difference and disconnection, through others' eyes, over and over (Charmaz, 2008). It is this sense of being different, of breaking the rules, and of feeling of less value – and, as judged by other people – that evokes shame. Nowhere, I would argue, might this be more likely to occur than in the often brutish realm of the workplace.

Shame is an experience of being in the world as an undesirable self, a self that one does not wish to be. It is an involuntary response to the awareness that one has lost status and is devalued by others (Poulson, 2000); it is a powerful, social emotion based on our need to feel connected with others, and that need to be connected can be threatened by relatively minor incidents (Kaufman, 1989; Scheff, 1994; Poulson, 2000). Key elements of shame include: a violation of some social role or standard; a failure to meet expectations; or, a perceived defect of the self that cannot easily be repaired (Lewis,

¹ I use the term 'disability' to include both chronic illness and disability.

1992). Shame has long been claimed to be predicated on social evaluations. Darwin (1871/1899: 114; Dickerson et al, 2004: 1195) described shame as being related almost exclusively to the judgements of others. Cooley (1902/1956), and Mead (1934), framed stigma, self-blame and self-esteem using the “looking glass self”, claiming that we understand ourselves by understanding others’ reactions to us, and that individuals continually monitor themselves from the perspective of others and, based on this, experience pride, or shame (Cooley, 1902; Mead, 1934; Else-Quest et al, 2009). Shame involves feelings of negative self-exposure in relation to the other (Persons et al, 2010) and is a self-conscious emotion experienced when a core aspect of the self is judged inferior or inadequate; importantly, it is provoked by the realisation that *others* consider one’s self to be deficient (Dickerson et al, 2004; my emphasis). Shame is a painful emotion that typically follows conduct or circumstances that damage self-respect (Persons et al, 2010). Pain, tension and arousal have all been linked to shame (Dickerson et al, 2004) and behaviours associated with shame all support the desire to submit and withdraw: individuals report wanting to hide, escape, disappear from view, or fall through the floor. They also express a desire to flee the social situation and conceal their “defective” self from social scrutiny (Dickerson et al, 2004: 1196; Karlsson & Sjoberg, 2009).

Having a disability remains highly stigmatised, with an almost inevitable link to Goffman’s notion of the spoiled identity (Goffman, 1963); the associated shame is linked to the rule-breaking character of the disease or disability in question (Nijhof, 1995). Concurrently, “health” remains the norm (Charmaz, 2008), and individuals remain perceived to be responsible for their health in Western societies (Frich et al, 2007). Any deviation, via a perceived failure to comply with either norms of health, or any perceived failure around health-related self-control (Frich et al, 2007) is liable to be viewed negatively, by both observer and observed. And shame is especially likely for people with disability at work, where expectations of continuing, high performance are uncritically held. Hay (2010: 260) described this as the “underbelly of a meritocratic cultural model of productivity and agency”, where expectations around one’s ability to “work”, “be productive”, and “be busy” are central to the Western daily lexicon (Hay, 2010: 260); people feel compelled to “use time wisely”, to not “waste time”; there is a moral compulsion to be productive at all times and this is considered a

defining characteristic of adulthood (Hay, 2010: 260). For those with disability, such as MS, shame linked with anticipated or actual disapproval of others around work is likely if such expectations are not met (Hay, 2010). And not only does shame feel bad, threats to the social self, or situations which demean one's social standing have been shown to increase cortisol levels, a hormone of the hypothalamic-pituitary-adrenal (HPA) system in those with auto-immune-related conditions (Dickerson et al, 2004; Gruenewald et al, 2004). In plain terms, feeling shame is bad for anyone, but can make people with some chronic health conditions even worse.

METHODOLOGY: SECONDARY DATA ANALYSIS AND CREATIVE NON-FICTION

WRITING²

Phenomenological Secondary Data Analysis

Phenomenological interview data from a study investigating the lived experience of life and work for people with MS was used here for secondary data analysis. Initial content analysis (Cavana et al, 2001) revealed an emergent theme of *Shame Experiences*. Such was the pain evident in respondent stories around this theme, combined with a literature search that revealed no earlier phenomenological studies of the Shame Experiences for workers with MS, the theme was considered worthy of further investigation. Zikmund (2003) described secondary data as data gathered prior to, and for purposes other than, how it is currently being used. So, while social researchers can and do use secondary sources as empirical evidence, so far, no one has worked out any clear, consensual rules and procedures for their valid use (Neuman, 2011). Given this absence of rules, I chose creative non-fiction writing to interpret the Shame Experiences shared here. Given the space limitations of this manuscript, just one case study (of a larger collective case study) is shared here.

The case study presented is intended to demonstrate one respondents' lived experience of shame around working. The case is used to explore, and analyse (Sarantakos, 1993) distinctions of

² The actual creative non-fiction writing process is detailed elsewhere (see, for examples, Vickers, 2010, 2011, 2012). However, I have endeavoured to be as transparent as possible with a view to assisting those wishing to embark on a similar path.

experience (Stake, 2000, p. 437) and this *particular* case was selected due to recognition of features, happenings, relationships or situations (Stake, 2003; my emphasis) considered central to learning (Stake, 2000) about the phenomenon under review – Shame Experiences for Workers with MS. Zikmund (2003) reminded us that exploring individual experience can serendipitously lead to unheralded discoveries, identification of relationships, events of interest, or other ideas that might shed light on previously unexplored phenomena. Readers are reminded that the findings are intended to be introductory and tentative, and generalising is not intended (Zikmund, 2003).

Creative Non-Fiction Interpretations

Academics have long explored novel means of sharing the experiences of research participants in an effort to enhance understanding. Some have used poetic, artistic and narrative devices (See Glesne, 1997; Furman, 2006a, 2006b; Vickers, 2006); others have utilised current works of fiction (Czarniaska, 2006, 2008); still others have devised fictional, semi-fictional or creative non-fictional accounts of the goings on in a myriad of social and organisational contexts (Spindler, 2008; Finley and Knowles, 1995; Gutkind, 2009; Clarke et al, 2005; Kettle, 2004; Rolfe, 2002; Vallant, 2005; Vickers, 2011). These approaches have been intended to stretch minds, engender curiosity, invite engagement and enhance understanding. Qualitative research should be a voyage of creation and discovery (Tierney, 2003); social scientists often do what creative writers do: they create rather than just discover; they focus on the unique and the individual; and they use illusion and rhetoric to make their case (Phillips, 1995; Rolfe, 2002). That was intended here.

The creative non-fiction scenes were developed and written from careful review, re-review, and interpretation of the phenomenological interview transcripts, combined with my research-based, and personal illness-related experience. At the time of conducting the phenomenological interviews used for secondary data analysis, I had published dozens of research articles (and two books) around disability and work, and had had MS myself for over twenty five years. During that time, I had experienced varying levels of physical disability, as well as many personal- and identity-challenges as a result of having MS. Creative non-fiction writers knowingly draw on imagination to supplement

empirical evidence (Miller & Paola, 2005; Rolfe, 2002) and I have long recognised the inexorable meshing of my lifeworld and research. I have consciously followed Mills' (1959) advice, that the most admirable thinkers do not split their work from their live and have endeavoured to put my particular vantage point to good use. Freeman (2004) refers to the value of using the rich and limitless source of data colloquially referred to as "life itself", and confirms that researchers who enable the interplay of structured and rigorous field work with "life itself" can move the research process beyond the usual, and allow researchers a different relationship with the data (Freeman, 2004). Undertaking the process of creative non-fiction writing allowed me to do just that.

Finally, I made selective interpretive choices, and pared away details in order to arrive at a coherent, readable "emotional truth" (Miller & Paola, 2005: 83; Roorbach, 2008) of respondent reported experiences. I make no claim that the scenes shared actually took place *exactly* as described, or that those depicted in the case actually said or did *exactly* the things depicted here.

A CREATIVE NON-FICTION, COLLECTIVE CASE STUDY

Case Study: Roland

The Creative Non-Fiction Case Study³ below includes empirical evidence of the *Shame Experiences* of "Roland." It includes: (1) *Contexts of Shame* (a contextual summary of key (non-fiction) demographic data in standard prose); (2) *Narratives of Shame* (non-fiction respondent phenomenological interview data); and, (3) *Scenes of Shame* (creative non-fiction scenes developed to bring to life the non-fiction evidence of Shame Experiences).

Contexts of Shame

At the time of interview, Roland was working 24 hours a week in a policy development area in a large, not-for-profit organisation. He lived with his wife, Suzanne, and 24 year old son. Roland reported

³ **Author's Note:** Creative non-fiction can include characters and events that have been compressed, changed, combined, added to, or imaginatively recreated. Where episodes are imaginative recreations of truth, they are not intended to portray actual events. Rather, texts are based on reported lived experience; any dramatisations are intended, primarily, to share the emotional truth of that reported empirical experience (Roorbach, 2008).

having commenced an undergraduate degree, but not completing it. Roland's first MS symptoms included numbness in both his hands, and severe fatigue. When he was diagnosed, more than 10 years later, he also reported having severe fatigue, and his hands stopping working altogether. At the time of interview, Roland was a wheelchair user (recently moving from manual to electric) with continuing, significant fatigue, nerve and skeletal pain, numb and cold feet, spasms in his legs, blurred vision, epileptic fits daily, and ongoing bowel and bladder dysfunction.

Narratives of Shame

MV: So you've been there two months, you've got this diagnosis [referring to his then recent diagnosis of MS]. It's a big shock. You tell this guy [referring to one of his colleagues of the time] and the Managing Director finds out. So, what happened then?

Roland: They started making my job unbearable. I know they had people from the [Industry Peak Body] come in and, I found out later, that was to find out how they could get rid of me legally. They made my position redundant but they didn't sack me. They gave me another position and the other position took me from working in an air conditioned office with a company car, to up a flight of stairs, and no proper air conditioning, and the company car was taken off me as well. And everything: I started getting emails everyday about, "you've made a mistake here", and "you've done this wrong". But it was to the ridiculous stage . . . my job was just made to go from Management to an Estimator . . . [and] the other staff were obviously told, it was fairly obvious they were told not to have anything to do with me. I was given a set lunch time, by myself. I wasn't allowed in the factory.

MV: You weren't allowed in the factory?

Roland: I wasn't allowed in the factory. I wasn't allowed near or in the factory at all.

MV: Did you not need to go to the factory to do your job?

Roland: Yes, I did . . . [and] in March it was still hot, so I couldn't get up the stairs. I got to the stage where I had to, he [the Managing Director, and the stress he created] just brought on exacerbation after exacerbation. A few times I virtually crawled up the stairs to get to where I was working. . . .

MV: Tell me, when you had to drag yourself up the stairs to get to your office and other people were presumably able to see this, some of them, how were you feeling about that?

Roland: [Long pause] I was already humiliated because the job role had changed. It was humiliating. But, look, I was just so fatigued I ended up spending weeks in bed. And even then, he rang up and told my wife, "Tell him to get in here. There's nothing wrong with him." He knew exactly what he was doing. It was as if he'd contacted the MS Society and got books on MS and was doing the opposite of what you're supposed to do with MS.

Scenes of Shame

Roland looked at his computer screen with concern. What a week he'd been having; first the MS diagnosis, now this. On the screen was an email from his Managing Director (MD) who, on his best day, Roland thought to be an organisational psychopath.

Roland took a deep breath and moved the mouse to click open the email. Any email coming from the MD wasn't likely to be good. In light of his what he now realised was a foolish disclosure of his MS diagnosis to his "trusted" buddy, Jason -- who he now knew to be one of the MD's favoured consorts -- Roland prepared for the worst. The subject line of the email read, "Position Review". Taking another deep breath, Roland double clicked his mouse and waited:

Dear Roland,

A recent organisational restructure has just been completed. As a result of advice from the Special Manufacturing Industry Association [a pseudonym], it has been noted that several of the roles here at Super Manufacturing Pty Ltd [also a pseudonym] have now been made redundant. Your current position was one of the roles requiring change in order for us to secure ongoing industry accreditation. This email is to inform you that your current position of Production and Control Manager has now been made redundant.

Your new role will be Production Support, Special Projects Officer. As a result of this position change, you are asked to immediately vacate your current ground floor corner office, located here in the Main building. Ben Stoner will shortly arrive from Security to assist with

the immediate removal of your personal effects to your new office, which will be, upstairs in Building D Annex, to Room D.2.07.

For your comfort and safety you will find an electric fan has been placed in your new office, and Ben will assist in opening the window for you, if required. Finally, you are to immediately relinquish the keys of your company vehicle as, in your new role, you will no longer require its use.

As if on cue, Roland heard a knock at his office door. Without waiting for Roland to invite him in, Ben Stoner brought his heavy-set, security-uniform-clad self into Roland's office, and marched around Roland's desk to stand beside Roland, without a word. Roland took a deep breath, trying to block thoughts of his mortgage and son's outstanding school fees from his mind. As he exhaled, Roland looked up at Ben, who smirked, raised his eyebrows, and held out his hand for the car keys. Roland slumped back in his chair and reached into his trouser-pocket, before dropping the car keys onto Ben's grimy palm.

"Roland's not able to come to the phone," said Suzanne, a scraping edge to her voice. She was standing in the hallway next to the phone, just outside their bedroom, where Roland was resting, as he had been for the last few weeks. "And he's certainly not returning to work tomorrow," she said. "As I told you before, I will put the Doctor's note in the post, tomorrow. It's all in there."

"Tell him to get in here. There's nothing wrong with him," Roland heard the MD yell down the phone line at his wife. He watched as his wife moved the phone away from her ear.

"I'm sorry, but he's really not well," she said, her face now flushed, and hung up the phone.

Looking in at Roland, she put her hands on her hips. "That guy's a monster," she said. "It's as if he's contacted the MS Society, got advice, and done the opposite of what you're supposed to do".

Roland nodded, and said nothing, as he watched his wife stomp back up the hall to the kitchen. He lay back and closed his eyes, wondering how he could ever go back to that place.

DISCUSSION

The Shame Experiences shared here confirm that shame is about being and feeling undesirable, unworthy, devalued -- just not good enough. Shame is experienced as a feeling of indignity, of defeat, or inferiority -- a wound felt from the inside, dividing us from ourselves and from others (Kaufman, 1989). Roland's Shame Experiences were felt through humiliation. Being a skilled worker, doing a good job, and pulling one's weight are regarded as outcomes about which workers can feel proud (Rantakeisu et al, 1999). For Roland, however, after disclosing his MS diagnosis, he found himself being shamed and harmed: physically (via reduced access to air conditioning, and having to now walk up and down stairs to get to his office); financially (via his reduced status and skill level job role, and loss of the use of a company car); and socially (via social isolation at work, loss of work responsibility, and having to crawl up the stairs to his new office when unable to walk up them in the normal way). Shame is experienced as feeling completely exposed and conscious of being looked at (Erikson, 1994) and key aspects of shame include feelings of violation and degradation in the eyes of others (Lewis, 1992; Scheff, 1994; Rantakeisu et al, 1999). This can result from negative and condescending attitudes -- such as those demonstrated by Rolands' manager -- of people with perceived higher status (ie able bodied, or more senior) to perceived lower status (ie disabled, or less senior) (See Starrin, 2002). Roland's story also confirmed his physical health deteriorating as a result of this, with his MS reportedly showing lots of flare ups ("exacerbation after exacerbation", and needing to crawl up stairs) and his general wellbeing and mental health being negatively impacted.

The literature confirms shame associated with adverse mental health and wellbeing outcomes, with shaming and associated financial distress interaction effects also being found to directly impact wellbeing, activity levels, and social support (Creed & Muller, 2006). Further, shame has also been directly linked to negative physical health outcomes in autoimmune conditions (of which MS is one) as a result of increased cortisol levels (see Dickerson et al, 2004; Gruenwald et al, 2004). In plain terms, experiencing shame can make people with disability, such as MS, even worse. Roland's reported need to spend weeks in bed confirmed this. Roland also demonstrated the phenomenological

response to his evaluation of shame: He wanted to hide, to disappear (Starrin et al, 1997; Poulson, 2000; Nijhof, 1995); and we know that any protracted state of shame will usually give rise to the physical avoidance of that social situations (Eales, 1989) – Roland was dreading returning to work. Unfortunately, if he left this workplace, Roland would have then faced a different shame; that of being unemployed in a society that values constant work output and endless contribution.

CONCLUSION: WHAT HAS BEEN LEARNED?

As we have seen, Shame Experiences for people with MS may be responsible for *unnecessary* suffering, and an *unnecessary* withdrawal from the workplace. Further interrogation of the Shame Experiences for workers with MS (and other disability) is required with a view to increasing employment inclusion because: (1) The employment prospects for people with disability, such as MS, are very poor; (2) Traditional policy solutions and legislative solutions have not been working; (3) Shame Experiences for people with disability, especially at work, remain inadequately investigated, even though the stigma around disability has long been the subject of worthwhile debate (see, for examples, Goffman, 1963; Lewis, 1992; Charmaz, 2008; Vickers, 2000, 2001, 2012; Millen & Walker, 2001); (4) Shame can harm one's emotional, psychological, financial and physical health; and, (5) The evidence presented in this case reconfirms that Shame Experiences contribute to suffering, and may motivate people with MS to exclude themselves from work as a result. For Australians with disability -- 45 per cent of whom live near or below the poverty line -- it is time to revisit employment questions. Unless the entire spectrum of workplace experience for those with disability – including shame experiences – is well understood, policy initiatives are unlikely to assist. Finally, shame is an *internally derived emotional response* and, as such, one potentially influenced by attitudes either from those in the community that an individual finds themselves, or internalised by that individual (Persons et al, 2010; emphasis added). This makes shame amenable to change through psychosocial intervention (Persons et al, 2010): if we change the way people with disability feel at work, we can reduce Shame Experiences. Further research on the Shame Experiences of people with disability at work is urgently required.

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