

Disability, relationship, and the negotiation of loss

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ABSTRACT

Oppressive stereotypes of invalidity and tragedy have positioned loss and grieving as contested issues in the field of disability studies. Ascriptions of 'denial' are rejected by many disabled people, as a reductive medicalisation of their lived reality. For these and other reasons, this paper asserts that disabled people are afforded limited or awkward social spaces for grief, be it to do with social positioning, embodiment, or any other aspect of human experience. This is significant because grieving may have an important relationship with political mobilisation, both personal and collective. The paper presents autoethnographic material from the life of the second author, who has lived with quadriplegia for more than three decades. Using ideas from critical psychoanalysis it traces how political, relational and intrapsychic mechanisms constrain and sanction his expression of feelings of loss, contributing to a relational predicament of *melancholic suspension*, analogous to that attributed to subordinated racial groups. Here, one is forced to strive for assimilation into an unattainable, ideal social role, while simultaneously being alienated from one's inner experience, with implications for both creativity and personal power. The paper concludes that, paradoxically, stereotypes are countered not by dissociation from grief, but rather the claiming of it.

INTRODUCTION

The notion of loss and grieving occupies a contested, politically charged place in the field of disability studies, as well as in the discourse of disability politics more broadly. At issue is the age-old ascription of stereotypes of damage and invalidity to disabled people, who are understood as being defined by a tragic loss of normalcy and vitality. Besides creating a false binary between the presumed perfection of the normate body (Garland-Thomson 1997) and the defectiveness of the disabled figure, this view presents disabled people with the medicalising injunction to strive for acceptance of socially engendered inequality disguised as natural fate—an imperative which many disabled people understandably take exception to (Watermeyer 2009; French 1993). But grief, we believe, is important in the lives of people who live with socially engendered disadvantage, as well as the often difficult effects of impairment. Amid this confusion, the central thesis of this paper is that disablist society markedly reduces the space available for people with disabilities to grieve, for experiences of exclusion, issues of embodiment or any other combination of life's adversities. In addition, we argue that this silencing has implications for the possibility of flourishing in the lives of disabled people (Clifton, Gwynnyth, and Shakespeare 2018). As readers of this journal will know,

the historical application by rehabilitation science of bereavement models to the onset of disability has often pathologised disabled people, through the attribution of emotional distress to the *problem of denial*—that is, an inability to accept impairment (Watermeyer 2014). Such thinking reduces experiences of loss in the lives of disabled people to difference or dysfunction of the body, circumventing an examination of how adventitious disability will also always bring social disadvantage, borne of devalued identities and an exclusionary world. In short, it makes sense of social ills by blaming the victim.

In this paper, we examine the ways in which a society troubled by the spectre of disability both assumes and silences loss in the lives of disabled people, considering implications at both an individual and collective level. To do this, we use autoethnographic data from the life of the second author (VM), who has lived with quadriplegia since 1987, when he was 19. The narrative material is interwoven with resonant experiential and theoretical reflections from a classic autoethnography on paralysis—*The Body Silent*, by Robert Murphy (1987)—which, in our view, elaborate and reinforce the argument. What makes the account unique is our highlighting of the ways in which, at different points in VM's story, the space afforded him to process feelings of loss is by turns limited, awkward, unsupported and negatively socially sanctioned. The story of VM's journey into, and with, disability is traumatic and extreme, but we are curious about how the silencing of emotion he experienced is indicative of a trend in relational dynamics surrounding disability which make it hard to grieve.

Further, we believe that the capacity (and opportunity) to grieve for the unique losses which a disabled person's experience of herself and the world can afford has important personal and political implications. Along with Cheng (2000) and Butler (1997), we are interested in how the sociopolitical predicament of *melancholia* plays out in the lives of disabled people (Watermeyer 2016), as it alienates individuals from internal experiences of socially engendered loss, precluding feelings such as rage, and the collective mobilisation which can emanate from it. The onset of a severe disability such as paralysis brings massive changes to embodied experience, as well as barriers to participation, discrimination and stigma (Abberley 1993; Barnes 1990; Linton 2006; Murphy 1987; Shakespeare 2013). In the language of the capabilities approach (Nussbaum 2009), these changes have significant consequences, resulting in the need for an individual to 'rethink and reshape their vision of flourishing, and learn new virtues to bring that about' (Clifton, Gwynnyth, and Shakespeare 2018, 21). To achieve



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this after an experience of traumatic loss, one's life-narrative must be reorganised, even rewritten, in order to create a 'new strand of continuity that bridges the past with the future in an intelligible fashion' (Clifton, Gwynnyth, and Shakespeare 2018; Neimeyer 2001, 264). In these conceptual terms, then, losses need to be grieved in order that a new life-narrative can be created, which makes possible the development of new capacities for flourishing.

In a thread of theoretical contributions, the first author has explored the ways in which relational forces place limits or prohibitions on the entitlement of disabled people to grieve (Watermeyer 2009, 2013, 2014; Watermeyer and Swartz 2008, 2016). In working through VM's story, we aim to track the mechanisms—political, relational and intrapsychic—which have disallowed grieving in his life since becoming severely physically impaired.

From here, the paper will proceed as follows: We begin with a short theoretical discussion on disability and loss, and how this relationship has implications for the politics of social change. Thereafter, VM's story is presented in eight segments, which he writes in the first person. After each of these, we offer a theoretically informed discussion of how at that particular stage the experience of loss was disallowed, displaced or otherwise made impossible by a combination of relational, structural and psychological factors, a reality corroborated and explored by Murphy (1987) in his autoethnographic work. What emerges is how VM's social milieu repeatedly fails to provide an accepting and safe place to grieve, limiting support available for the challenge of making sense of loss, and reauthoring his life, which he faces. The paper concludes with a summary of the argument and some implications of the silencing of grief in the lives of people with disabilities.

CONSIDERING LOSS

In her seminal essay, French (1993) described how both loss and denial in her life as a disabled child were not individual phenomena, but the product of relational dynamics in which others were both consciously and unconsciously invested. She carried projections of loss from others, while also being drawn into publicly denying her experience of disability in order to protect those around her. Along similar lines, Murphy (1987, 20) describes how people enduring physical struggle such as paralysis who nevertheless continue to 'smile and joke' will be 'honoured by all'. Because cultural stereotypes of damage and tragedy cluster so readily around the disabled figure, people with disabilities may be reluctant to express emotional vulnerability of any sort (Watermeyer 2009). This is because to do so is to risk ushering in a pre-existing imago of the *invalid* or *cripple*, leading to further invisibility, rather than becoming more known by others. Consequently, disabled people may find themselves behaving, even thinking, in a manner which strives to disconfirm assumptions about who they are, rather than explore and elaborate who they might be (Watermeyer 2009). This can lead to an alienation from the thread of loss which runs through any life, disabled or not, supporting a defence against the reality that loss is what binds us all as members of the human family, not what divides us. None of this is to imply that disability does not bring experiences of loss; instead, what is rejected is the culturally condensed idea that positions disabled people as the primary, if not exclusive, custodians of loss. For all humans, the ability to grieve for one's losses is essential to emotional well-being (Freud 1917; Frosh 2006; Klein 1959), and in order to do this we need the acceptance and containment of another, whom

we trust sufficiently to show ourselves to in times of vulnerability (Winnicott 1965). Again, for everyone, cultural constraints which disallow expression of vulnerability must be negotiated, but these may be especially severe and complex in the lives of disabled people. Fallacious ascriptions of tragedy culturally cement loss to the lives of disabled people, while simultaneously displacing the voice of real experience, and the all-too-familiar, universally human griefs which this may expose. Put simply, the societal gaze needs to decide what the experiences of disabled people are, because to listen would be to risk exposure to griefs that are not disability-specific, but universally human.

Cultural forces which preclude grieving have, in recent times, been understood as a key factor in maintaining social inequality (Watermeyer 2016; Butler 1997; Cheng 2000). Oppressed groups who carry devalued identities are vulnerable to what Cheng (2000) terms *melancholic suspension*, in which the societal injunction to strive for a mandatory, yet unreachable, cultural ideal carries one far away from one's own grief, and the political and personal power which it can bring. Grieving involves self-compassion and a lived acknowledgement of the gravity of one's social suffering (Kleinman, Das, and Lock 1997), be it to do with race, gender, disability or any other axis of social injustice. Rather than being a sign of vulnerability, therefore, the capacity to grieve may be an essential part of growing collective political action, a process which goes hand-in-hand with the reauthoring of one's life-narrative. Indeed, Murphy (1987, 157) comments that:

The most lasting benefits of any struggle against perceived oppression are not the tangible gains but the transformations of consciousness of the combatants.

To this end, Watermeyer (2016) reframes loss in the lives of disabled people as something to be claimed, rather than disavowed, reaffirming its place as an essential and universal aspect of being human. In what is to follow, we believe there is a strong demonstration of how this 'claiming' needs to be deliberately undertaken and supported, if recovery from trauma and the grieving of loss, is to be provided for.

Here follows VM's story, divided into eight thematic segments and interspersed with theoretically informed commentary. The segments trace a long-term process but are not strictly sequential, nor are their characteristics mutually exclusive, but instead have been separated out for the purpose of conceptualisation.

We meet VM as a 19-year-old, in his first year studying fine art at university. He is well liked, academically successful and an avid sportsman. One night his father is driving him home from the university studio and a massive tree falls and part of it hits their car. His father is killed, and VM wakes up in an intensive care unit with quadriplegia.

VM'S STORY

Introduction

I turned 19 at the end of August 1987 and met and entered a relationship with a lovely girl in September. Life was great. This all changed on 4 October that year. I was working late in the darkroom at university and my father came to pick me up at 9PM after attending a social event with my mother. On the way home we were in a road accident in which my father was killed, and I was paralysed from the shoulders down. My life as I knew it had turned completely upside down.

Being overwhelmed by trauma

I lay in the intensive care unit straight after my accident and nothing seemed real. The suddenness of my newly broken body, my new disability, was incomprehensible, and the time spent in rehabilitation

was an emotional rollercoaster. I had lost my father and I had lost the ability to move my arms and legs. My sense of loss was overwhelming, and it felt like it would never ease. Nine days after my accident my head was incredibly itchy as there was still blood and bits of glass in my hair. The nurses washed my hair for me, and I immediately began to feel relief. At the same time, I felt so sad that they had to do this and started crying uncontrollably. It was my first real taste of the loss of my independence. One of the nurses recognised this and asked me if I was feeling bad because they were washing my hair for me and I replied “yes”. She told me that they were here to help me and that I must not feel bad. However, I remember feeling lost inside and devastated that I had to rely on others for this simple task.

At this early stage, directly after a catastrophic life event, VM was in a state of profound psychological trauma. Suddenly, and with no warning, nothing was like it had been before, and he was plunged into feelings of shock and disbelief. This is the nature of trauma, in which one experiences events which are so far beyond one’s frame of reference and modes of coping that they are impossible to locate in terms of subjective meaning and the continuity of life (Herman 2015; Kaminer and Eagle 2010). Instead, one may feel like the ‘stranger in a strange land’, imagining that it may all be a dream, a mistake. At this stage, the new realities of life were yet to begin to come into view, and hence nowhere near possible to grieve. The meaning of VM’s experience, thus, remained hidden, internal and obscure, until it began to be realised in the world, through the washing of his hair by the nurses. This moment appears to have begun his inauguration, in real, relational terms, into a new social positioning and relationship with agency, which felt utterly devastating. The loss of much of what had gone before slowly came into view. But how does one begin to grieve a loss which is so complete, so indescribable? In order to begin the task of moving beyond disbelief, reliable, secure and accepting support is an essential point of departure, but in many ways what was to come in VM’s world was far removed from this.

‘This is not me’

I believed I would simply get better and walk out of hospital. I was in denial of my situation and wanted to rebel against it in any way possible. When I got up in a wheelchair for the first few months, I wore the hospital issue clothing which comprised dire khaki colour cotton shirt and trousers that looked like prison pyjamas. I wore these clothes as a badge that I did not belong here. It felt like the only bit of protest that I had. I also asked for a nice photograph of myself hiking taken before the accident to be on the shelf close to my bed. Somebody asked my mother why the photograph was there, and she said correctly, “Because Victor wants people to know him as he was and not as he is now.”

As the shapes of VM’s new material surroundings became more defined, his psychological ‘solution’ was a reflex to disidentify with all that he perceived. What he saw was becoming real, and his quite natural response was to reject it. In what occurred around the hospital clothing and the photo, his only means of emotional survival was to decide that this was ‘not me’, as nothing in his new world made sense. One idea which came upon him was that he was being somehow punished for an offence he had not committed, and therefore that the ‘punishment’ could not be real. As noted in the previous section, the processing of grief during this acute stage of psychological trauma is not humanly possible. Further, integration of such realities into one’s life-narrative and identity cannot be taken on alone. From here, VM needed strong allies, whom he could trust to withstand his new story, a story he was not yet able to articulate or hold. Bion (1962) conceptualises emotional containment as the experience of being ‘thought about’, that is, a clear sense that someone else

is able to hear and hold one’s story, without rejection, retaliation or withdrawal (Rustin 1991). It is this containment which grows self-acceptance, through the integration into personal identity of feelings and memories which previously felt unbearable. In one sense, we are all asking one another the same question: ‘*Can you stand me?*’ Murphy (1987)’s own answer on this is clear, as he describes how cultural and relational forces positioned discussion of his disability experience as strictly out of bounds. He notes that no one has ever asked him about his experience of paralysis, as ‘this would violate all the rules of middle-class etiquette’ (p87). As VM’s story continues, we will see how a pattern of factors precluded the space for grieving, as he moved back—in a conditional way at least—into the social world.

Losing independence

As bad as life in hospital was, there was routine and structure and regular contact with people. When I came home there seemed to be nothing but tragedy, loss, isolation and survival. There was only my mother and me, my dad was gone. The immediate priority was my health and how to cope with my paralysis on a daily basis. During the first year of being home I experienced recurring bouts of bladder infections, diarrhoea and fevers. Worst of all, I was dependent on my mother for everything. She had to give up work and her entire life revolved around looking after me. I was the reason she was tired all the time and I just felt like a tremendous burden to her. I was an only child and we had been a close-knit family, and I tried to be myself and my dad for my mom’s sake. I felt guilty that I could not contribute. I lost the ability to feel proud as a son and felt that I should have died with my dad so she could have got on with her life. A few years later my mom went overseas for a couple of weeks. I was 21 years old and had two nurses working for me, however, I still felt like a scared little boy who had been left alone because I had come to rely on my mom being there, not just physically but also psychologically. I felt ashamed for being so scared but found it difficult to think beyond that.

Suddenly fully reliant on his mother for survival, VM was thrust into a relationship of profound and continuous mutual dependency. While his mother cared day and night for his physical needs, he was left with constant feelings of guilt at her new burdens, as well as awareness of her grief, both for her husband and her son. She cared for him physically, and he felt responsible for her emotionally. This overlapping and confusion of psychic boundaries is a by-product of care relationships surrounding disability, which can threaten self-expression, agency and a healthy self-identity (Watermeyer 2013; Watermeyer and Swartz 2008). In societies where inaccessible environments make reliance on personal assistance a daily reality, the social imperative for disabled persons to remain grateful, humble and unassertive can shape entire lives.

In order to grieve, we need the containment of an accepting other, someone who we trust to be receptive to our chaotic emotions and help us digest them (Bion 1962; Winnicott 1960). This means trusting that the other will not be overwhelmed by our feelings, become angry or withdraw. VM was acutely aware of the colossal stress and emotional pain which his mother was experiencing, leaving him feeling too racked with guilt to find the strength and entitlement to share his inner life with her. While Murphy (1987, 92) regards guilt as elemental to the cohesion of all modern families, this is dramatically elevated surrounding disability, becoming the very ‘life stuff’ of relationships. What was occurring between VM and his mother would become a blueprint of sorts, as he continued to discover how little space would be made for him in the social world for communicating experiences of his new body and social positioning. Against the backdrop of a world which demands ‘normalization’, disability

experience has been conceptualised as cultural matter out of place (Douglas 1966; Garland-Thomson 1997), which must be kept to oneself if one is to be granted admission to the social world. Disability-related loss carries that much more valency, as cultural associations with disability impute it with little else but observer fantasies about its *horrors* (Watermeyer 2009, 2014). As argued by Watermeyer (2009), the fact of disabled persons being bombarded with projected fantasies of loss creates a situation in which one is left attempting to disprove who one is assumed to be, rather than exploring and expressing who one is. Amid this struggle to shake off a devalued, imputed identity, few resources, both internal and external, are available for the work of finding and articulating what one's losses really are.

This is the essence of what, in theoretical work surrounding unconscious aspects of racial inequality, has been termed *melancholic suspension* ((Watermeyer 2016; Cheng 2000), about which more later.

Whose loss?

My father was very well liked, and his sudden death came as such a shock to those who knew him. The nurses commented on how they kept seeing these grown men coming to see me in ICU and walk out crying, many of them had played soccer with my dad and had watched me grow up. A friend commented on it and I said they find it difficult to handle and he replied, "What do they have to handle?" While I was still in the rehabilitation ward a close friend opened up to me that he was really battling to accept what had happened to me and my dad. I responded by saying that I was strong and that I will be okay. This became a common trend with me and was perhaps a coping mechanism. I gave off a tough exterior and my general response was that I was strong and coping. It was my way of having some control and protecting my friends. I found myself taking a hypocritical stance as I became more of a disability activist. In public I went on about how much people with disabilities suffer and are discriminated against. However, to my friends and family I presented a facade that I was fine, and everything was okay.

Even while still in hospital, VM found himself drawn into the role of reassuring others, in the face of their being overwhelmed with grief. If one is positioned as the 'bringer' of emotional pain to others, although through the luck of misfortune, one readily feels responsible for shouldering the burden of feelings in the room—indeed, one may feel that one's continued belonging in a valued relationship or in a network is contingent on doing so. VM's emotional-relational predicament began taking shape as a double-bind. In many situations, such as the foregoing, it was impossible to grieve because of the proximity and vulnerability of others. However, at other times he found himself increasingly isolated, without the acceptance and support essential to allowing oneself to move into dangerous emotional waters. He was by turns with others who needed protection and afforded guilt or left alone with no one to rely on or to show his pain to. This seems like the worst of both worlds, leaving pain lodged underground.

Isolated, dissociated

After coming home from hospital, I saw very little of people. The house became something of a time warp, everyday seemed the same and life outside was passing us by. My mother and I felt very excluded and forgotten about. Most of my friends were leading the student life and I felt robbed of all this. Usually, when I met people as a young student, they would ask me what I was studying, and did I have a girlfriend. Now that I was in a wheelchair, people just wanted to know what happened to me, and beyond saying how sorry they were, it went no further. It became a lot easier for me to live in my head and cut off from everything happening around me. It was very difficult to participate in society at that time. I was paralyzed and I

was ostracised, my wheelchair got me moving around again but did not get me accepted, in fact, it felt like the opposite. There were very few places that were accessible in Cape Town, or indeed throughout South Africa as a whole. In that sense, my mother and I were forced to stay at home most of the time and so lost the ability to go see friends or interact with anyone on a regular basis.

When confronted with the confusion of overwhelming grief and abandoned to it by the withdrawal of an anxious social world, there is nowhere to find refuge but within. Without the stimulation of the outside world, or the enlivenment of relationship, VM found himself slipping into dissociation, as the weeks and months of unchanging drudgery and sadness in the home piled upon one another. Through the acute phase of a traumatic episode, the nature of defences which are harnessed to manage intense emotion set the pattern for how the new reality is dealt with on an ongoing basis. In other words, if one is not supported through a trauma, and forced instead to rely on oneself, the assumption that others are unable to cope with one's pain may harden, making it more difficult to trust and rely on others in the future. Murphy (1987)'s experience echoes this, as the onset of paralysis caused him to wish 'more than ever' to be 'left alone' (p92). He goes on to warn, though, that withdrawal can lead to a compounding of feelings of damage and guilt, as these have nowhere to go. As noted, the ways in which powerful feelings evoked by trauma are responded to in the short term can have formative implications for how one copes in the new life which has begun, potentially cementing defences such as withdrawal (Watermeyer and Swartz 2016).

The ascription of a devalued social identity, in combination with the disallowing of expressions of emotional aspects of one's new life experience, provides the conditions for a socially engendered state of melancholia (Butler 1997; Cheng 2000). While it has roots in Freud (1917) *Mourning and Melancholia*, Cheng's notion of racial melancholia diverges significantly. For Freud (1917), melancholia was an individual, pathological state of insoluble grief for the loss of people, places or things, leading to an intractably depressed mood. Applied to disability, this original iteration of the idea evokes the tragic stereotypes of the medical model (Oliver 2009)—that is, the offensive caricature of an invalid stuck in mourning the loss of an ideal body. By contrast to Freud (1917); Cheng (2000)'s concept of melancholia is a non-pathological group experience, manifesting the emotional consequences of a denigrated social identity and the imperative towards assimilation. African Americans, in her view, are placed in the impossible predicament of being required to rehabilitate their damaged black identity through striving for the ideals of cultural whiteness, while simultaneously being precluded from achieving them. This subjective positioning can make grieving for the reality of socially engendered loss impossible, and with it the self-realisation and political empowerment which such emotional shifts may unlock. Instead of settling into a recognition of one's own losses, and from there beginning to create a new narrative of life and identity, the obligatory orientation is outward, towards an apologetic striving to compensate for one's obvious damage. Watermeyer (2016) applies these ideas to disability oppression, arguing that the social imperative to strive for normalcy, as well as unspoken prohibitions on expressing disability-related struggle, place constraints on the processing of grief in the lives of disabled people. Of course, the griefs imagined here are by no means exclusively about impairment, but relate to a complex, intertwined array of losses as much to do with social positioning as with embodiment. In VM's life, the destruction of so much of what he loved, valued and enjoyed coincided with the assertion of socially engendered constraints

on his expression of emotion—a phenomenon familiar to persons who sustain adventitious disability (Watermeyer and Gorgens 2013). The assertion that the silencing of emotion is a key aspect of social oppression has roots in critiques of colonialism. For example, in his theory of the mind of the colonised, Frantz Fanon (1963) describes the *mechanisms of concealment* of emotional aspects of struggle as a key obstacle to be overcome on the journey to liberation. Picking up on this, Murphy (1987) believes that such feelings, if not made a place for, may ultimately be turned inward on the self.

Being unreal to belong

Many friends that I had known for a long time did not know how to treat or regard me anymore. It felt like I had lost what I was to people, and how they related to me. When I saw them occasionally there was no automatic conversational go-to place, like “Hi, how are you doing? How is your dad? What have you been up to? Who is playing on Saturday?” All these questions were replaced by an interminable heaviness. People did not want to keep reacting with sadness and simply did not know what else to say. Everybody moved on while my mom and I were stuck in our house in our tragedy and loss and we got left behind.

The friends with whom VM had identified, and felt a sense of belonging, were, naturally, who he needed to tell of his distress, and feel understood by. But the very fact of their intimately knowing him, and therefore of carrying their own grief and confusion, seemed to make it hard for them to stay present and listen. As noted earlier, the ascription of loss to the lives of disabled people has typically been part of a pathologising, othering view, which reduces the distress of exclusion to the problem of ‘denial’ (Watermeyer 2014; French 1993). However, as should be clear from the current discussion, ‘disability loss’ is not an individual or solipsistic phenomenon, but something negotiated in social systems characterised by constraints on what can be said, and hence felt. Drawing on anthropologist Mary Douglas (1966)’s notion of cultural *matter out of place*, Garland-Thomson (1997) conceptualises disability, and our feelings about it, as an awkward social excess, which must somehow be done away with if collective well-being is to be restored. VM’s friends were choked with their own unmanageable feelings, not just about the catastrophe that had befallen him, but about the shared fragility of bodies and lives, and an abjectness at the core of the human condition. This, alone, was too much, ironically leaving no place at all for the receiving and containing of the feelings of the person who was inhabiting the daily, embodied reality of unfolding trauma. From his vantage point as someone living with quadriplegia, Murphy (1987, 117) observes it thus:

The disabled serve as constant, visible reminders to the able-bodied that the society they live in is shot through with inequity and suffering, that they live in a counterfeit paradise, that they too are vulnerable.

Wherever disability and inequality are found, guilt is never far away (Murphy 1987; Watermeyer 2013). The overturning of VM’s life placed a gulf between his world and that of his friends. Crashing inequality now separated them, in their opportunity to participate in relationships, outings and activities, learning and careers, and every other aspect of the social life of young, middle-class people. Such inequality can feel unbearable for everyone; it is excruciating and senseless to suddenly be deprived, baffling and unspeakable to continue having. Faced with these odds, it appeared that an unspoken compromise was reached, in which everyone withdrew in acquiescence to the idea that the social system could not withstand the situation’s contradictions. The

complications being faced here are reminiscent of what Goffman (1963) termed the ‘primal scenes of sociology’ (Murphy 1987, Goffman 1963, 136). In these scenes, an interaction carries (subjectively, at least) some overpowering flaw, which ‘robs the encounter of firm cultural guidelines, traumatising it and leaving the people involved wholly uncertain about what to expect from each other’ (Murphy 1987, 87).

In collective as well as interpersonal terms, when relative deprivation is acute, it will, to some extent, resolve into othering. Continuing to see the ‘deprived’ other as the same fellow-human that he or she was exposes one to the fracturing contradiction of inequality. A fantasy that he or she is now somehow inherently different can provide refuge—a defence which is commonplace in justifying a myriad forms of social exclusion of disabled people (Watermeyer 2013). Linton (2006) describes how, in a first conversation with a close friend after an accident in which she became paraplegic, she instantly found herself taking the reassuring role, saying that she was ‘OK’. Her friend exploded at this, saying that this could not be so, as ‘you’re fucking paralyzed!’ For Linton, the experience was a powerful affirmation that she was still the same person to her friend, still fully in the world of shared humanity, and not relegated to the silent othering of unreal, watchful relating described by many persons with visible impairments (Watermeyer and Swartz 2008).

An othering gaze

It felt strange how society regarded me as this tragic figure and expected me to behave in a certain way. I remember going to a friend’s house for a barbecue. Someone pushed me into the room at the back of the house while my mother parked our car. As I entered the room, I was feeling awkward but duly smiling and saying hello to people I had never met or hardly knew – but they knew my story or had read about it in the newspaper. These people were now staring at me, or what I call non-staring, where they turn their faces to look away as if focussed on something else. I wanted to jump up and down and scream at these people that this is not really who I am – this was a terrible thing that happened to me, it’s all a mistake, come talk to me for 5 minutes so that I can show you that I’m not stupid, that I am quite bright and sometimes funny. I could not act naturally. It was as if I had been branded, people saw me coming and did not know how to react. They were all uncomfortable and I was the reason for it.

In the face of a gaze saturated with imputations of damage and shame, such as that experienced here by VM, many disabled people describe a drive to disidentify with loss altogether. In these circumstances, showing any sign of vulnerability will usher in the confirmation of a disablism stereotype which exists in the mind of the observer, both invalidating and silencing the life of the disabled person before them (Watermeyer 2009, 2014). It can lead to the alienation of a mode of being in which one seeks to disprove who one is assumed to be, rather than explore and express who one is—the essence of a melancholic predicament (Butler 1997). This shutting out of one’s stream of experience, of feeling, can be mirrored and concretised by the exclusions of the material world, which is suddenly riven with tangible barriers. As there is no place for the body, there is no place for emotion and experience; all have become *matter out of place* (Douglas 1966, Garland-Thomson 1997). For VM, the experience at the barbecue painfully underlined how for others it had become too emotionally risky to allow him to continue occupying the role of simply another human being. Instead, his difference was reified, fundamental and profoundly separating. At other times, VM experienced sanctioning of his emotional expression which was far more explicit:

On another occasion, I got into an argument with a guy who had parked in a disabled parking bay. I got really angry with him and he turned away during our argument and said to himself, “jeez, so angry for a disabled guy.” His comment made me livid. It felt so disempowering that I was not supposed to get angry because I have a disability. These moments when I expressed my true feelings and they were invalidated I found difficult to accept. So, a kind of falseness developed, I began to behave in certain ways to make people feel more ease around me so that I could feel included, even though I was not seen as an equal.

The madness of inequality

The year of my accident was 1987 and South Africa was still ruled by the apartheid government, which meant segregation and inequality between black and white. Consequently, there were separate wards for white patients and for black patients at hospitals. Soon after I was given my motorized wheelchair, I started to explore the hospital grounds on my own. I came across several isiXhosa men who were lying down on their stomachs on long stretchers that had wheels at the front and back so they could push themselves around. A nurse explained that they had pressure sores that were healing around their buttocks and coccyx areas. The nurse further explained that some of them had had skin graft operations and that after a couple of months of healing, many of the men would rip their sores open again on purpose. Rather than go back to their respective homes around the country, where they faced the constant struggle of poverty and neglect, they decided it was better and safer to stay at the hospital for as long as they could. Unlike their homes, it was a place where they received medical care, three meals a day and had a warm bed to sleep in. I remember feeling numb and heartbroken at hearing their stories. It was incomprehensible to me. I could not imagine spending one more day than necessary at this terrible place, especially considering the worse conditions in the dirty and overcrowded black wards. I also could not imagine being so desperate that my only option for survival was to rip my skin open to expose a gaping wound. To me, the hospital had become a cesspool of humanity and I could not wait to leave. It began to dawn on me, however, that despite everything that had happened to me, I was lucky to be able to leave.

The macabre inequality witnessed by VM at this early stage further disrupted his entitlement to grieve, presenting him with a conundrum which remains unresolved more than 30 years later. VM is middle class, holds a PhD, owns a home and can afford the personal assistance he needs. As a disabled South African, his education and resources put him in a tiny minority. As he moves through his life, confronted daily by the force of an embodied experience which he describes as ‘defeating’, and facing regular disablist prejudice and exclusion, he cannot but compare his ‘fortunate’ position with the lives of disabled people in poverty. It is difficult to imagine the seismic psychological experience of a contradiction between devastating trauma on the one hand, and the baffling experience of simultaneously being ‘fortunate’ on the other. The complex, even paradoxical relationship between race-based and disability-based disadvantage in postapartheid South Africa has been considered elsewhere (Watermeyer 2019). How does one make sense of being terribly unfortunate (the essence of trauma), and, at the same time, utterly fortunate? How can one grieve one’s losses when the misery of others is so appalling, so palpable? This is a dilemma not peculiar to disabled people, but one which cuts across social identities which attract disadvantage in a variety of ways—one may experience racism, but not poverty, poverty, but not disability, gender-based violence, but not racism, and so forth. Having said that, however, the question of entitlement—to grief as well as much else—is one with specific significance to the disability community. Continual experiences of exclusion can undermine one’s sense of belonging, rendering a subjective state which feels precarious and contingent. Added

to this, inaccessible environments feed dependency on assistance, supporting the need for a stance of gratitude and accommodation in return. All of this militates against a position of openness, curiosity and compassion in relation to one’s internal world, as entitlement to have and to belong can mirror the entitlement to feel (Watermeyer 2014).

Interestingly, VM describes how grappling with being ‘fortunate’ also became his healing and ‘salvation’. Over years, and then decades, he has done development work among disabled people in some of Cape Town’s poorest communities. Here, he continues to find purpose, a daily opportunity to work through the material contradictions of one of the world’s most unequal societies, and to reaffirm experiences of commonality based not only on disability, but on humanity itself.

CONCLUDING REFLECTIONS

VM’s story as a disabled person has been told here in a manner which highlights a continuing pattern of psychosocial circumstances which made it hard for him to grieve. In the period soon after his accident he was, as any mentally healthy person would be, overwhelmed by acute psychic trauma. Conscious grieving for one’s losses is impossible at this stage because, first, the losses themselves have not yet fully come into view, and second, emotional reverberations are too powerful and amorphous to make sense of. During this phase, all VM could do psychologically, in order to regain some sense of control, was to disidentify with his new reality. Finding himself at home, and under the round-the-clock care of his mother, new obstacles to identifying and expressing feelings became apparent. His mother was psychologically devastated and physically exhausted, and he felt a guilt-ridden need to care for her emotionally, and become both father and son in the household. The reality of physical dependency surrounding disability, especially in the context of an intimate relationship, can profoundly constrain honest emotional expression. Without freedom to speak and be heard, one’s chaotic internal world has little chance of being understood, by oneself or another. Even in external relationships, VM discovered that he had to cultivate an unreal persona in order to belong. The grief of others at his loss, combined with their guilt, left little or no space for the containment of his feelings. Part of this predicament was the frank requirement that he reassure others which, by definition, made it impossible for him to express distress. When not disguising his feelings in company, he was left alone, without the basic support and understanding which anyone would need in order to process overwhelming emotion. The new world for him involved being pulled into relations of melancholia which required assimilation to an unattainable ideal, while alienating him from his own experience and even creativity. Finally, the South African sociopolitical context of massive inequality lent his struggle a quality of the absurd, as his suffering was set up against the lives of those who were ‘obviously’ far worse off.

In all of these ways, VM was not afforded sufficient space, support, acceptance and freedom to grieve. He regards the consequences of this reality for his personal development as very significant, noting, too, that working on this paper has been in part a cathartic and healing experience. If Cheng (2000), Fanon (1963), Butler (1997) and others are correct, finding a voice for emotional aspects of oppression is key to change. Fanon (1963), in particular, emphasises that the most important change which this brings is not to the ‘world out there’ but to the inner life of people who have internalised oppression. Disability grief seems so aversive, so disquieting to modern society. Somehow, a place must be made for it.

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