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Writing on Disability and Illness, and the Case for Self-reflexive Storytelling

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Abstract

This article examines two exemplar texts, both memoirs written by mothers about their sons, and discusses the altruistic motivation for using self-reflexive writing techniques in narrative representations of illness and disability. Through an analysis of texts by authors Rachel Adams (2013) and Anne Deveson (1991), the article explores the pros and cons of vulnerable writing about oneself and others, including the author's own children and family. Much is at stake for Adams and Deveson as they write about deeply personal experiences and feelings, and in doing so share the lived experience of disability (Down syndrome) and mental illness (schizophrenia) and broader issues around parenting, difference and identity. It is proposed that researching and writing with reflexivity not only allows writers to better understand themselves, but also opens the door to reader empathy, creating a sense of connection for readers. Furthermore, the examined texts by Adams and Deveson illustrate how vulnerable writing can be a form of advocacy as the authors promote a greater understanding of the ethnographic subject matter by pushing against assumptions, breaking down stereotypes and making the personal, political.

Introduction

I would like it very much if you thought of me as a mouse telling you a story, this story, with the whole of my heart, whispering it in your ear in order to save myself from the darkness and to save you from the darkness, too.

Kate DiCamillo (2004). The tale of Despereaux, p. 270.

A couple of days after giving birth to her son Henry, Rachel Adams (2013) lay in her hospital bed and re-read the book *Life as we know it: A father, a family and an exceptional child* by Penn State University Professor Michael Bérubé. It was the second time she had read the book about Bérubé's son Jamie who was born with Down syndrome. The first was as a graduate student, before climbing to the ranks of professor at Columbia University, and before the thought of starting a family of her own. Bérubé's book took on new meaning the second time Adams read it as she had just been told that her new baby Henry had 'features consistent with Down syndrome' (p. 28). She writes in her own book, *Raising Henry: A memoir of motherhood, disability and discovery* (2013), about the despair she felt at hearing the news about Henry's condition, and the subsequent sense of hope and connection she and her husband Jon attained from reading Bérubé's book. She later explains at a lecture (as recorded in *Raising Henry*):

Of course we knew that Henry would be an individual with his own personality and abilities – not a clone of Jamie... but in the first weeks of our son's life, *Life as We Know It* became our guide, a portrait of what it might mean to have a person with Down syndrome in our family (p. 207).

With this sentiment in mind, Adams set out to share her own experiences. She wanted to provide a source of connection for others in need, all the while continuing to draw on Bérubé's book as a source of inspiration. 'As scholars we aspire to write books that will enlighten and inspire our readers', she told the same lecture audience. 'Some of us succeed. But it is the rare literary critic whose books also offer wisdom and comfort in a time of crisis. Michael's book did precisely that for me and my family, and for numerous other parents I've met in the years since Henry was born' (p.208). Ironically, Adams' own book *Raising Henry* has taken up where Bérubé left off, reaching a new audience of parents and other readers interested in understanding Down syndrome and the complexities of parenting a child with a disability.

Like Adams, I have found solace in reading stories while negotiating life as a parent of a child with difference. Immersing myself in the stories of writers such as Adams has helped me to better comprehend my own situation and to know I am not sailing solo on a vast ocean. They have also alerted me to the plight of others. As communication scholar Arthur P. Bochner (2013) writes: 'There may be no better way to come to terms with how we want to live and what we can say about how others live than to listen to their stories' (p. 54).

Interestingly, the narratives I have felt most drawn to are non-fiction and autobiographical in nature; works in which the writers want their readers to take what they say personally. It is a style that ethnographer Bud Goodall (2000) describes as 'writing that rhetorically enables intimacy in the study of culture' (p. 14). I have enjoyed a further level of such intimacy through writing stories and hope to eventually engage in storytelling's reciprocity, widening the 'circle of shared experience' (Frank, 1995, p. xii), sharing my own story and the experiences of other families living with high functioning autism. Drawing on interviews, the writing project I'm working on fuses autobiography and ethnography, and as such I have turned to the methodology of autoethnography: 'connecting the autobiographical with the ethnographic to tell stories that are informed by and help make sense of lives in cultural context' (Boylorn & Orbe, 2014, p. 17).

Autoethnography as a methodology 'allows the author to write in a highly personalized style, drawing on his or her experience to extend understanding about a societal phenomenon' (Wall, 2006, p.1). It draws on the assumption that researchers can never truly be objective, and that research will always be told from their perspective. The practice of self-reflexivity is not unique to autoethnography, but has been commonly used in research whereby 'the researcher pauses for a moment to think about how his or her presence, standpoint, or characteristics might have influenced the outcome of the research process' (Wall, p. 3). In autoethnography, however, self-reflexivity extends beyond a token gesture and instead, introspection is actively drawn upon as a source of rich data (Wall; Holman Jones, Adams & Ellis, 2013).

Admittedly, autoethnography is not a methodology I enter into lightly. Personal narrative, particularly the use of self-reflexivity within my writing makes me uneasy. I find it confronting and at times overwhelming. Sometimes I am so saturated in the reality of the subject matter that I cannot bear to write it down. I am also cautious about disclosing personal information about my family and my interviewees. The ethics process involved in writing a project through a university certainly addresses many of the concerns I have. However, being a fairly private person and a protective mother I can't help but intuitively question my choice of personal writing over a more objective format. Here I borrow sociologist Marjorie L. DeVault's definition of personal writing as 'sections of text that present autobiographical or introspective material in the service of a sociological analysis' (1997, p. 218). Such writing brings the emotional qualities of research to the fore, drawing to attention the researcher's affective responses to fieldwork or study. A certain level of courage is needed when making such personal writing public. As autoethnographer Carolyn Ellis suggests, a vulnerable writer cannot hide behind the façade of objectivity and will invariably 'open [them]selves up for criticism about how [they]'ve lived' (2004, p. 24). Subsequently, this essay seeks to ask: how does self-reflexive writing serve to enhance a qualitative research project? How can vulnerable writing contribute to social research on disability and illness? And ultimately, is it really worth throwing oneself into the void?

Before taking such a leap of faith, it helps to look at how others have leapt before. As such, this essay analyses Adams' book *Raising Henry* and journalist Anne Deveson's book *Tell me I'm here* (1991) with the view to assisting me with the task of critically examining my own research and writing practice. Both exemplar texts are memoirs written by mothers about their sons, and both are valuable pieces of research that share the lived experience of disability (Down syndrome) and mental illness (schizophrenia), and broader issues around parenting, difference and identity. Although quite different in their setting and mood (*Raising Henry* is uplifting while *Tell me I'm here* is harrowing and tragic), the books share several important features that illustrate the motivation behind utilising the techniques of personal storytelling. While neither writer expressly classifies her work as 'autoethnographic', I turn to this methodology in order to better understand the authors' intentions and outcomes. Both texts certainly fit the various definitions of autoethnography, including '[A] form of self-narrative that places the self within a social context. It is both method and a text, as in the case of ethnography' (Reed-Danahay, 1997, p.9) and '[A]n approach to research and writing that seeks to describe and systematically analyse (*graphy*) personal experience (*auto*) in order to understand cultural experience (*ethno*)' (Ellis, Adams & Bochner, 2011, p. 1).

Taking account of the autoethnographic nature of the exemplar texts, I examine how Adams and Deveson negotiate emotion, analysis and political issues (Ellis, 2004). I also consider why the authors have chosen such personal methods of qualitative research

and writing to achieve their purpose and how reflexivity can be used as a source of data to illuminate the research and to understand the social context they are researching (Holman Jones; Adams & Ellis, 2013). The image of a bewildered Adams lying in her hospital bed soon after giving birth to Henry brings home the value we place in stories in times of need and how they can enlighten. Such stories of lived experience, even the most seemingly mundane of moments, illustrate the complexities of life and help to inform the cultural and the interpersonal (Boylorn & Orbe, 2014).

Raising Henry

As the sub-title of her book attests, *Raising Henry: A memoir of motherhood, disability and discovery* sits within the literary sub-genres of motherhood and disability memoir. However, beyond this literary classification, Adams' work is one of social research. When I interviewed Adams about her writing process in 2015, she revealed her primary intentions in writing *Raising Henry* were to connect with a readership (R. Adams, personal communication, 5 March 2015). Still, I was intrigued as to why she felt compelled to write such a personal account of family life when she could have written an academic publication on Down syndrome. A Professor of English and Comparative Literature, Adams juggles her time between literature, cultural studies and disability studies (an area she specialised in even before the birth of Henry). She is President of the Columbia Center for the Study of Social Difference, and her book *Sideshow U.S.A.: Freaks and the American cultural imagination* (2001) examines the politics of freak shows (a fascination she openly grapples with in *Raising Henry*). Despite her wealth of experience and knowledge of disability studies, *Raising Henry* is not an academic text. Asked whether she had an audience in mind, and if she was writing from the point of view of a parent or academic, or both, she responded:

I did want to reach a broader audience so it was very gratifying to me to write a book that parents could read, after having written several very academic books. I give it to the teachers at my son's school and they read it. They understand it. But I also wanted to write a book where I could introduce a lot of the intellectual problems and the social and political problems that come up around the challenges that we are confronted with, having a child with disabilities. I think of it as criticism by stealth, that I try to tell a story and along the way, to work in the issues rather than segregating them in a way that would allow people to skip and think 'oh this chapter is the chapter where she becomes more theoretical, I'll just skip that and get back to the story'. That was my strategy and I really wrote it to connect with people (R. Adams, personal communication, 5 March 2015).

Adams' research is largely informed by moments of introspection as she looks reflexively at both theory and the interactions with those around her. She considers how who she is shapes not only her professional and parenting decisions, but also her interpretations of research data. She writes with honesty and intimacy about the juggle of motherhood and the inevitable resentment that comes with caring for a child with a disability (within her busy lifestyle as a self-professed overachiever). Such confessions are a refreshing change to the parenting manuals or mainstream media articles that focus on being the 'perfect parent' or parenting the 'perfect child'. Furthermore, Adams' self-deprecation, as well as her observations of her personal discomfort and confusion

add context and the nuance needed to fully illuminate the subject. It sheds light on the experience and consciousness, and the scope of human endeavour. Ellis (2004) refers to this when describing the 'multiple layers of consciousness' that autoethnography requires:

Back and forth autoethnographers gaze: First they look through an ethnographic wide angle lens, focusing outward on social and cultural aspects of their personal experience; then, they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations (p. 37).

It is through Adams' looking outward and inward that readers piece together the complexities of the issues at hand: complexities that include the physicality of Henry's disability, the juggle of managing parenthood, the financial cost of having a child with a disability and many other broader issues of a sociological nature. Through self-reflexivity Adams not only attempts to understand her own unique experiences, but also helps readers become more attuned to the experience of parenting a child with Down syndrome.

At times Adams places herself on the line and by writing with great openness she raises inherently political issues. For example, she grapples with the 'confusing and contradictory messages that surround the notion of reproductive choice in our culture' (p. 102), analysing her own choice not to have an amniocentesis test when pregnant with Henry. She writes:

I know. This is shockingly risky behavior on the part of an ambitious, overeducated, overachieving person like myself. Amnio was made for people like me, women with a deep need for order and control and perfection. Women who strongly believe in the right to abortion. Technology was supposed to liberate the woman who needs to know she will never have to be the mother of a child like Henry. So what the hell was I thinking? (p. 89)

Adams goes on to explain why she chose not to have the test (a combination of previous experience and also being told her chances of having a Down syndrome child would be a one in two thousand). She also discusses how, had she had the amniocentesis test, she may well have aborted and Henry wouldn't exist. She subsequently reflects upon the very idea that a Down syndrome foetus should be terminated: how genetic testing has become routine and where do we draw the line?

Soon it will be possible to detect any number of features in a developing fetus, including hair and eye colour, potential height, weight, and intelligence. Many people believe there is an ethical difference between tests that would identify such 'designer' genetic characteristics, and those intended to determine the health of the fetus. But how do we decide what counts as health and what constitutes a disease? (p. 105)

By opening up a line of enquiry about sociological values, Adams' text becomes more than just a memoir of personal discovery. It becomes a rigorous piece of research,

ethnographic in nature, one that examines the culture the author has come to inhabit. Such personal storytelling, writing from one's own experiences, can provide a means for better understanding individuals as cultural beings, thereby helping to critique beliefs and practices (Holman Jones; Adams & Ellis, 2013; Boylorn & Orbe, 2014).

This is where the personal meets the political, as highlighted by the ethnographer Ruth Behar (1996), who writes that the '[p]ersonal voice, if creatively used, can lead the reader, not into miniature bubbles of naval gazing, but into the enormous sea of serious social issues' (p. 14). Adams raises social justice questions around such issues as disability, parenting and feminism. Her book draws on history and academic theory, including her own dissertation on 'freaks'. In *Raising Henry* she writes extensively about her fascination with the culture of freak shows and her admiration for the freaks who were upfront about their extraordinary characteristics, all the while encouraging the reader to question societal attitudes toward disability. Through reflexivity, Adams also questions her stand on these issues, writing:

Of course, Henry wasn't a freak. But as I tried to figure out what was best for him, it became harder and harder to separate my personal and my academic interests. I found my experiences as a parent increasingly in tension with ideas and beliefs that had been integral to my intellectual landscape (p. 199).

Throughout the book, Adams is candid about her personal and professional choices and, as such, the reader garners a greater understanding of disability issues, including the juggle of managing therapy appointments, the pressure placed upon family relationships and siblings, and dealing with judgmental attitudes. She combines her academic research about disability with her lived experience as a parent and eventually, the personal and professional align in the form of advocacy, writing:

Once I came to see, in a very personal way, the importance and value of including people with disabilities, it was impossible not to want to change my world. I realized my work wasn't just about words on a page. I could use it to do something very real and very important (p. 206).

Through writing her book, Adams becomes a narrative crusader, harnessing the potency of personal storytelling to enrich a broader understanding of Down syndrome and other disabilities.

Vulnerable writing on illness and disability

Mattingly and Garro (2000) write:

[i]n giving voice to illness experiences, narrative is seen as providing a phenomenologically attuned means for enacting bodily experience (p. 27).

Narratives allow storytellers to communicate what is significant in their lives and the audience to infer something about what it feels like to be a part of that. On illness narratives, Mattingly and Garro note:

Narratives offer a powerful way to shape conduct because they have something to say about what gives life meaning, what is inspiring in our lives, what is dangerous and worth taking risks for. Compelling stories move us to see life (and act out life) in one way rather than another (p.12).

Personal storytelling allows readers to identify and connect. As Behar (1996) argues: 'When you write vulnerably, others respond vulnerably' (p. 16). But it is risky behaviour. Indeed, a common fear among writers is that they will be criticised by their peers for being unnecessarily self-indulgent. Because of its subjective nature, autoethnographers are often dismissed as using biased data or for being 'self absorbed narcissists who don't fulfill scholarly obligations of hypothesizing, analyzing and theorizing' (Ellis, Adams & Bochner, 2011, p. 283).

Behar notes that autoethnographers open themselves up to the possibility of being wounded or attacked:

[W]hen an author has made herself or himself vulnerable, the stakes are higher: a boring self-revelation... is more than embarrassing; it is humiliating (p. 13).

This 'vulnerable self' is, however, the jewel in the crown for autoethnography and without exposing it, research is simply 'ethnographic' and seen through a 'wide angle lens' (Ellis, 2004, p. 37). Beyond oneself, this vulnerability extends to others who may be implicated in autoethnographic work.

Sometimes these 'others' are interview subjects, or they may be close and intimate family members, as in the works of Adams, Deveson and my own project. Protective devices such as the use of pseudonyms can go partway in considering the sensitivity of personal stories. However, it is ultimately up to the researcher to decide what stays in and what is left out. In my own research, I find myself asking pressing questions such as: are the stories of my subjects in fact mine to tell? And if it comes down to a cognisance of what is right and wrong, what makes me right? Ellis, Adams and Bochner (2011) consider ' "relational concerns" as a crucial dimension of enquiry that must be kept uppermost in their minds throughout the research and writing process' (p. 281)

Autoethnography as both a process and a product is not clear-cut. It is not an approach that seeks 'certainty, closure and control' (Berry & Patti, 2015). For that reason, it would seem to suit the lived experience of illness and disability, which is often chaotic, confusing and messy. Self-reflexivity and vulnerability in writing can address this encompassing perspective of health and illness, and can raise ontological questions and phenomenological concerns that traditional medical data may overlook (Mattingly & Garro, 2000; Goodall, 2001; Richards, 2008; Carel, 2008). Arthur Kleinman (1988), psychiatrist and author of *The illness narratives: suffering, healing and the human condition* says that when he refers to "illness", he 'mean[s] to conjure up the innately human experience of symptoms and suffering' (p. 3). Illness and disability goes beyond the physiology of a person to encompass their relationships with partners, friends and family, their work, their finances, daily routines, self esteem: a whole gamut of emotions. Furthermore, some illnesses are stigmatised and shrouded in metaphor, with blame

placed on the shoulders of the sufferers (Sontag, 1991; Richards, 2008).

Susan Sontag has argued that the way we interpret some metaphors can have negative consequences – such as stigmatising an illness or disability, promoting fear or discouraging people to seek treatment earlier. In *Illness as metaphor* Sontag draws on the examples of AIDS and cancer with the most far-reaching metaphors being ‘military’ in nature, including the use of words such as “invasion” of a disease, the body’s “defenses”, the way a treatment “kills”. She writes that the military metaphor:

... overmobilizes, it overdescribes, and it powerfully contributes to the excommunicating and stigmatizing of the ill (p. 180).

Of the stigma surrounding AIDS, she writes: ‘[t]he unsafe behavior that produces AIDS is judged to be more than just weakness. It is indulgence, delinquency – additions to chemicals that are illegal and to sex regarded as deviant’ (p. 111).

Another stigmatised condition that comes immediately to mind is autism, with blame often placed on the shoulders of the parents. The ‘refrigerator mother’ theory of the 1960s suggested that ‘an emotionless parenting style caused the child to develop autism’ (Rajendran & Mitchell, 2007, p. 225). More recently, a now discredited study published in the *Lancet* journal connected autism with the MMR vaccine, prompting many parents to stop vaccinating their children. Other parents were blamed for already causing autism in their children (Kirkland, 2012).

For her part, Adams addresses stereotypes surrounding Down syndrome through the use of personal narrative in *Raising Henry*. She writes about how she also takes an interest in the use of narrative within the medical settings she attends with Henry. She is familiar with the importance of medical narrative having worked within the realm professionally, however she takes up the cause even more fervently when she encounters the impersonal approach of certain doctors. One male geneticist appears to use Henry as a teaching tool, poking and prodding him and showing residents the physical characteristics of a Down syndrome child. She writes:

I perched on my seat, silent and incredulous. It was 2009. We were sitting in the office of a respected hospital in New York City, but this felt too much like a freak show, with Henry and me as the main attractions (p. 113).

Determined for the medical professionals to see her and Henry as more than just patients or curiosities she begins to hold talks with geneticists and other doctors, and parents. This is outside of her academic role, from the perspective of a parent. She writes:

Professors in the humanities have been skeptical of personal experience as a source of evidence. We say that people are unreliable narrators, no better at representing their own feelings and experiences than anyone else. True enough. Still, this was a situation where personal experience made me an authority simply because it was mine. It wasn't the kind of authority I enjoyed as a tenured professor. I wasn't claiming to speak for other people, or to know everything. I was just talking about the things that had happened to me to an audience that believed those things were worth listening to. It felt so simple and genuine, and I found it very gratifying (p. 119).

Adams also finds writing about her experiences immensely gratifying. Initially she writes to make sense of her situation, but she then begins to acknowledge her 'participation in a broader collective experience':

I started to see my writing not only as a way of capturing the particularities of my own experience but as a way to communicate with other parents and even to talk back to the doctors and researchers and anyone who went around spouting outdated and incorrect information about Down syndrome (p. 115).

As Adams attests, narrative can offer a therapeutic exploration of crucial issues for both writers and readers. As such, autoethnographic stories are written for and with readers in mind wherein 'each, teller and listener, enters the space of the story for the other' and engages in the 'reciprocity that is storytelling [whereby] the teller offers herself as a guide to the other's self-formation' (Frank, 1995, pp. 17–18).

Bochner (2013) writes of 'autoethnography's existential calling' (p. 50). Inspired by the humanistic psychologists who study the full scope of human experience, he claims that autoethnography is a response to the need for the human sciences to address such experiences. Bochner writes that autoethnography is 'a response to an existential crisis – a desire to do meaningful work and lead a meaningful life' (p. 53). It is inquiry that encourages greater understanding, not in a morose fashion, but in a way that is engaged with life 'in short, to make happiness more probable' (p. 54). Self-reflexive narrative is of enormous value for researchers who are interested in comprehending both unique and ordinary human experiences. It can benefit the teller, bringing about clarity and catharsis, but it can also similarly benefit the reader. The narrative form engages readers and encourages them to recognise themselves and their experiences.

Tell me I'm here

Like Adams, Anne Deveson writes intimately about her family and, in particular, her son Jonathan. Published more than two decades ago, *Tell me I'm here* is a potent and deeply affecting account of Jonathan's tumultuous battle with schizophrenia, his gradual descent into madness, and his tragic death of an overdose at the age of 24. Set against a backdrop of Australia in the 1980s when there was greater stigma surrounding schizophrenia, the book has since become a classic. It is significant not only for its groundbreaking and revealing approach to schizophrenia but because of the way it forges connections with readers.

As is often the case with illness narrative, the text serves many purposes, from personal

story to reference book and social commentary. After writing the book, Deveson went on to set up the Australian organisation SANE and advocate for schizophrenia in other ways. As a writer, Deveson is well aware of the responsibility bestowed upon her and reflects in the prologue on how her journey can reach out to others:

Writing this book has meant re-living periods I would rather forget ...
But our stories need to be told. How else can we know that others
tread the same pathways? How else can we find our healing? (p. 3).

In attempting to make sense of her own tragedy, Deveson utilises the form of the diary entry to immerse herself in introspection. The reader is subsequently privy to her innermost fears, and the complexities and challenges of writing about a subject close to her heart. Her research is multidimensional and by reflecting upon the ordeal of revisiting her life with Jonathan through her writing, she peels back the layers and reveals an autoethnographic 'vulnerable self'. This is particularly apparent when writing about such personal, painful material becomes too confronting for her:

I do not want to write this book. I find it painful ... It scratches old
wounds so they have no chance to heal. I am sick of the word
'schizophrenia'. I am sick of madness (p. 179).

The first-person diary format of *Tell me I'm here* allows the reader to witness Deveson's family life and day-to-day happenings. The routineness and ordinariness of events reveals a quietly resolute picture of life with schizophrenia, defying the stereotypes of its time. It is painfully honest in parts as Deveson explores the emotions of a mother watching her son's life unravel, and of letting go, all while she raises two other children and attempts to keep relationships and a career intact. Yet it is more than just a story of one family's life. As well as emotive, the book is factual and it is this combination of subjective and objective that shines light into dark, unexplored corners.

As a journalist Deveson would have been accustomed to research, but perhaps not such self-reflexive research whereby her thought processes are made present upon the page. Yet it is through an introspective writing mode that she is free to discuss her unspoken anxiety and fear. Such affective writing allows the reader to garner a tangible sense of Deveson's deep loyalty as a mother, and her inherent guilt and shame. Her inner conflict is understandable, as Jonathan's behaviour is at times quite erratic, especially when he threatens to kill her on more than one occasion. She writes of the inner turmoil she experiences trying to protect her child while also trying to demonstrate 'tough love' by encouraging him to take some responsibility:

I can't go on writing as I feel so distraught. How could I have done
that to my own son, when he was sick? How could I have turned him
out in the middle of a winter's night, when outside it was raining and
freezing cold? I can see the two policemen, shuffling their feet, not
liking what was happening, and one of them saying 'Please yourself,
ma'am, but they say blood is thicker than water' (p. 178).

Deveson's interior monologues help her to rationalise the irrational, and to connect with both herself and with her readers. As she tells, reveals and wrestles with her emotions, she produces 'aesthetic and evocative thick descriptions of personal and interpersonal

experience', typical of autoethnography (Ellis, Adams & Bochner, 2011, p. 277). In doing so, the reader is familiarised with her cultural experience, that is, one family's experience of living with schizophrenia:

Come off it, Anne, the reality is that in Jonathan's last two years, he twice threatened to kill you; he bit you, had his hands round your throat and semi-throttled you, hit you, terrorized Joshua, threw Georgia around; he smashed up your possessions in Sydney and in Adelaide. He ran away from every possible kind of help. He did not have to sleep in the park; he did not have to break into your house in the middle of the night (p. 178).

Arthur Frank (1995) might describe Deveson's narrative as a 'chaos' narrative. 'Chaos stories are sucked into the undertow of illness and the disasters that attend it,' writes Frank (p. 115). Events unfold as the storyteller experiences the chaotic nature of the illness experience unfolding. Chaos stories generally lack a coherent sequence and do not have what might be thought of as a 'happy ending'. This is in stark contrast to the 'restitution' narrative which has the plot line '[y]esterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (p. 77), and which tends to focus on returning to good health. Alternatively, the 'quest' narrative 'accept[s] illness and seeks to use it' (p. 115). Quest storytellers find alternative ways of being ill and subsequently realise a sense of purpose – a change in career or an inclination to write about one's journey. Most published illness narratives fall into this category.

Deveson's book could in fact be said to straddle both chaos and quest narrative. While her narrative is most certainly about a journey of illness, and the ominous reality of schizophrenia (chaos narrative), one of Deveson's primary objectives (like Adams) is to raise awareness and provide support for other families (quest narrative). The quest narrative, like most autoethnography, can provide the storyteller with a therapeutic outlet but it is also altruistic. By inviting readers to bear witness to inner processes and reactions the writer connects to the experiences of others outside his or her world. Within the realm of illness narrative Mattingly and Garro (1994) suggest that stories fill a void for people searching for an understanding of their illness, which may not be available to them in other ways. They write:

Narrative offers what is perhaps our most fundamental way to understand life in time. Through narrative we try to make sense of how things have come to pass and how our actions and the actions of others have helped shape our history; we try to understand who we are becoming by reference to where we have been (p. 771).

By intertwining the personal (Deveson's reflections), the cultural (where schizophrenia sits in society and within the family unit), and the anthropological (the facts about schizophrenia, the disease), Deveson reveals a great deal about Jonathan's illness and her experience as primary carer. Of illness narrative Mattingly and Garro (2000) write:

... [t]he telling of personal tales, intersected with observations of one's ethnographic subjects highlights the place of the anthropologist as personal witness (p. 21).

This reflexive and inter-disciplinary approach – the combining of anthropological, sociological and philosophical theory with human experience – creates a powerful text that can be both informative and moving. Deveson's research informs while her continual process of reflection allows readers an opportunity to empathise, identify and reflect on their own situations. As Ellis (2002) writes, increased self-understanding, 'going deeper inside yourself through autoethnographic writing', can provide a fast track to social change:

Expressing my feelings vulnerably on the page invites others to express how they feel, comparing their experiences to mine and to each other's...Good autoethnography works toward a *communitas*, where we might speak together of our experiences, find commonality of spirit, companionship in our sorrow, balm for our wounds, and solace in reaching out to those in need as well. (p. 401)

This is Franks' (1995) 'circle of shared experience', a view of autoethnography as a collective arrangement, opening up critical engagement with readers around social issues. This is of interest to me as I consider the direction and objective of my own research project. I am drawn to Adams' and Deveson's courage to give rise to political discussion through empathic writing. Not all of their writing is outwardly political, however. I find the most moving part of Deveson's narrative is her introspective material, and the passages where her experience as a parent who has witnessed the gradual decline and eventual death of her son are most prominent, such as in this imaginary conversation she has with Jonathan's spirit:

Okay Jonathan, so if I am going to finish this book, I have to make peace with you, because when I have been writing it for more than a couple of days, I begin to feel you with me.... You are here, but not here.

Do you mind that I am writing this book?

In a manner of speaking, no.

So does that mean No?

Yes.

What would you want me to say?

Tell it like it was for me.

I can only guess.

Tell it like I told you once – when I said, 'The message of everything is love, and I'm doing the best I can.'

The nearer to the end it gets, the harder it becomes. The file marked JONATHAN – DEATH is on the floor, and I keep kicking it away (p. 231).

Reading this dialogue, even for the fourth or fifth time, is incredibly moving. It still gives rise to a lump in my throat as I identify with the protagonist, Deveson, drawing on my own experience as a mother. I empathise or 'feel myself into her situation', sensing her grief for the loss of her child. I also reflect on my own current situation. A reader's

perspective plays an enormous role in the way narrative is perceived. Bal (1997) writes that 'each person brings to the [story] his or her own baggage' (p. 63), calling this the 'meta-narrative thrust' of a text (p. 63). Descriptions can prompt personal recollections and influence our emotional response to a literary text (Mar, Oatley, Djikic, & Mullin, 2011). Oatley (1994) calls this 'literary simulation', or 'identification based on mimesis as simulation' (p. 72). He outlines the range of emotions we feel when we immerse ourselves in narratives:

We may witness events and experience sympathies and antipathies, we may be stirred by reliving emotion memories, and we may experience emotions that derive from identification with one or more characters as we adopt their goals, run their actions on our planning processes, and discover these plans meeting vicissitudes (p. 72).

Subsequently, the reader can feel intrinsically linked to the protagonist's story, drawing on it to make sense of his or her own situation.

Narrative empathy and advocacy

There are several narrative techniques that may help facilitate empathy in readers. One of these is the use of a first person voice. Narratologist Suzanne Keen (2006) states that first person writing 'more readily evokes feeling responsiveness than the whole variety of third person narrative situations' (p. 215). But garnering reader empathy is not as simple as incorporating some first person writing. That is too broad an assumption. Keen suggests that writing in the first person may be a useful tool but there is more to the equation. The two most formally nominated features of narrative are 'character identification' and 'narrative situation'. Keen writes:

... character identification is not a narrative technique (it occurs in the reader, not in the text), but a consequence of reading that may be precipitated by the use of particular techniques of characterization (p. 216).

Aspects of characterisation can include names, descriptions, and the way things look and feel. Then, by reflecting and drawing on lived experience, readers assimilate the stories of others into their own situations (Mar et al., 2011). By placing him or herself in the shoes of characters within illness narratives the reader can more readily identify with them. Through a form of emotional contagion readers might 'catch' their emotions and empathise. And by reflecting on their own experiences and remembered emotions readers assimilate their current situations, leading to a greater sense of understanding and possibly, healing.

It is actually Deveson's hope that her writing can help readers come to terms with their own personal situations, and it is for this reason that her writing may be seen as a gesture of compassion. It is a cliché but 'information is knowledge', and the more that is known about schizophrenia, the more families can understand what they are grappling with and seek the appropriate help for themselves and their loved ones. By reaching out to a wide audience and using personal experience and perspective, Deveson endeavours to destigmatise schizophrenia by lifting the shroud of mystery and misinformation. She translates the phenomenology of mental illness, writing:

I needed to write this book to lay before myself, the richness of the experience and the bleakness. I needed not to deny the bad aspects because these were a part of the whole and, for me, serenity rests in the whole (p. 259).

Thus, her writing is a holistic investigation of the experience.

In exploring the negative and positive experience of mental illness, and expressing it on the page, Deveson (1991) makes peace with her emotions towards her son – emotions of anger and despair. Subsequently, she develops a greater understanding of how people with schizophrenia function, endeavouring to share her personal research on mental illness with her audience. Her concluding paragraph reads:

For too long, mental illness has been kept in the shadows. Instead of rejection, we need acceptance. Instead of shame, we need love. Instead of despair, we need solid and unwavering support. It is time to come out of the shadows and into the light (p. 261).

Indeed, this is the book's *raison d'être* and the message Deveson wants to leave her readers. Interestingly, she says the reason society is so fearful of mental illness is because we separate mind from body when really the two are integrated. Parallels can be drawn with Merleau-Ponty's idea that humans are 'embodied and enworlded' (as cited in Carel, 2008, p.13) when Deveson writes:

... [w]e are both mind and body; and we live within an environment which is also part of ourselves. Only now, as I approach this whole picture, can I begin to understand Jonathan's illness (p. 261).

Narrative has helped Deveson to better comprehend both her and Jonathan's place in the world. In addition, it has provided her a 'voice', subsequently helping others to empathise and understand a story that is as complicated as life itself.

Conclusion

The reality, of course, is that Deveson's story of mental illness is one that could affect any one of us, at any time, as could Adams' story of disability. Adams (2013) writes:

Even if we're lucky enough to avoid sickness and injury, we all grow older, facing the inevitable infirmities and weaknesses that come along with an aging body (p. 201).

Here I draw on Sontag (1991) again and her metaphor of illness as travel when she notes:

... [e]veryone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place (p. 3).

We are all travellers in our own unique way. Why then are we so afraid? And how do we overcome that fear? One way is through storytelling, through dispelling myths, sharing the truth and destigmatising.

Adams and Deveson are helping me to synthesise the challenges of an autoethnographic approach to my own project on high functioning autism. While I still find a degree of anxiety and discomfort in personal writing, I understand that the analysis of such tacit feelings illuminates the complexities of a multilayered subject matter, of parenting a child with difference and of autism itself. As I reflect upon my praxis, I am discovering that I need not disengage from the emotions I feel when writing or interviewing my subjects, and I need not dismiss my responses as unprofessional. Instead, there is value in observing why I am being brought to tears, feeling annoyance or rapture. Research and writing is undeniably subjective, however it is through an autoethnographer's reflexivity and through the process of writing that rich, humanistic issues unfurl. As Bochner (2013) argues:

Facts are important to an autoethnographic storyteller; they can and should be verified. But facts don't tell you what they mean or how they may make you feel. The burden of the autoethnographer is to make meaning of all the stuff of memory and experience – how it felt then and how it feels now (p. 54).

I note that it is in moments of introspective writing that Adams and Deveson are their most illuminating. I also observe the connection I sense as a reader when they write of feeling conflicted by their judgments and choices, exhausted by their subject matter, or when they are torn between writing their story or not. These empathic points are of interest to me, how they shape a reader's knowledge and understanding. Connection is a core principal of autoethnography's philosophy, which Bochner (2013) describes as 'a desire to do meaningful work and lead a meaningful life' (p. 53). For it is through evocation and a community of readers that autoethnographers can engage in social action (Ellis, 2014). Holman Jones (2005) writes:

Our autoethnographic texts do not stand, speak, or act alone; are not texts alone; and do not want to be left alone. I want to create a noisy and fractious dialogue on and about personal stories, performance, and social change. I want to stage this dialogue in and through the flesh of my own experience ... I want to suggest how we make our personal accounts count (p. 783).

Writing with reflexivity about our own insecurities and fears can help to show that all humans are fallible and that lived experience is complex and extraordinary. It can help to broaden understanding and build tolerance around illness, disability and difference. While such writing may feel uncomfortable or counterintuitive at times, it does seem that sometimes we must share our stories to find our bearings, and to help fellow travellers find their bearings too.

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