

## **Swinburne University of Technology**

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#### **‘You’re not going to magic away their disability are you?’: the ethics of magic and the ethics of realism**

##### Abstract:

Tuffrey-Wijne, Bernal and Hollins (2008) define ethical research as that which does no harm. As a writer with a social work background, my experience has been that ethical research also has a social justice component. As a practitioner I have always felt a strong obligation to enable young peoples’ voices to be heard. Researching the experiences of homeless young people, the Social Work Code of Ethics gave me clear boundaries and a clear notion of the very real harms that result from unethical practice. My choices in representing young peoples’ experiences in reports seemed straightforward. On the other hand, as a novelist writing young adult magical realism, I found unforeseen twists and dangerous tripping points. The process of representation was significantly more fraught.

My novel focuses on a group of young people who are outside the ‘normal’; living with disabilities such as Cystic Fibrosis and Williams Syndrome. To create true-to-life characters rather than stereotypes, it was important to interview young people living with these conditions. Applying for approval from the university ethics committee raised issues which my social work research experience enabled me to navigate, but the real challenge arose when the CEO of a support agency for those with Cystic Fibrosis asked me ‘you’re not going to magic away their disability are you?’ Writing fantasy, that had been my plan for the novel’s direction. Further, when I met young people with Williams Syndrome and their families, I felt an obligation not to stereotype their condition. I faced difficult questions around the interests of the story versus the interests of the populations depicted. Depicting young peoples’ experiences in their own words in reports is one thing, but attempting to write in their voice in a fictional piece is another.

I had to consider what harm, or good, a fiction writer can do. While there is always debate about the role of the writer versus the role of the reader in ascribing meaning to a text, theorists have argued that fiction has certain moral obligations because it can take us into another’s experience (Cosgrove, 2006; Le Guin, 2004), which can lead to empathy and understanding. In undertaking an autoethnographic narrative inquiry into these dilemmas I discovered that my social work practice could inform my writing practice, giving me a unique ethical perspective from which I could find a way to be true to both my research subjects and the interests of the story.

##### Biographical Note:

Rachel Le Rossignol holds a Bachelor of Social Work from the University of Sydney and a Masters of Creative Media (Creative Writing) from RMIT. She is currently working towards a PhD by Artefact and Exegesis at Swinburne University of Technology, Melbourne. Her artefact is an ‘eco’ themed young adult novel that sits somewhere

between fantasy and magical realism. Her exegesis examines how we can restore our relationship with the earth through the power of storytelling in order to envisage an alternative future to one of increasing climate disruption. Her work incorporates elements of ecofeminism, ecopsychology and narrative therapy.

Keywords:

Ethical narratives – disability – young adult fiction – autoethnography – identity – creative writing

## **Introduction: an ethical dilemma**

This paper undertakes an auto-ethnographic narrative inquiry into the ethical implications of writing a young adult novel whose central characters live with chronic illness or disability. The line of inquiry is how I reconciled my social-work ethics with my writing practice. Epistemologically I have come to an embodied understanding of ethical practice through twelve years' experience as a social worker whose focus often included the ethical dimensions of non-fiction, ethnographic storytelling. However, when a dilemma arose while undertaking research for my novel, I had to consider what ethical imperatives exist for a writer of fiction, and consequently identified tensions with my social-work ethical position. As I sought to reconcile the two, the methodological approach of practice-led research led me to discover that my social-work skills 'toolbox' offered a unique prism through which to examine the question of ethics in fiction writing.

The following anecdote illustrates the dilemma at the heart of this paper. Early in my PhD process, I sat in a CEO's office, clutching my ethics approval paperwork, prepared to explain my research methodology, aims and professional background. I hoped to interview teenagers with Cystic Fibrosis. In twelve years as a professional social worker I had often met with staff of youth welfare organisations, and knew they were justifiably protective of their vulnerable clients. But the CEO's first question was one I had never encountered before. 'You're not going to magic away their disability are you? Because it wouldn't be fair. They'll never be free of their illness. There's no magic solution for them.' I knew, from Smythe and Murray that 'ethical responsibility for research participants begins at the recruitment stage of narrative research' (2000: 325). I discovered in that moment that 'ethical responsibility' has different implications for a creative writer than for a social worker.

## **Ethical understandings in social work**

During my social-work career I negotiated some difficult ethical situations and, guided by the AASW Code of Ethics, developed skill in reflecting on my practice from this perspective. I strongly agreed that 'theoretical knowledge and clinical skills form a necessary but not a sufficient condition for effective family centred practice', because 'values govern all intervention, the core value being respect for the individual' (Scott & O'Neill, 1996: 41).

In 1997, in the establishment of a family reconnection service for homeless young people and their parents, the political expedient was to 'get young people back home'. Yet I knew that forcing them home placed some at risk of abuse: for them, re-establishing communication between teenager and parent was usually the best 'reconnection' outcome. Although this stance was highly controversial, I felt an ethical imperative to ensure the Federal Government heard young peoples' stories which had, until now, been drowned out by biased media discussion. Our final report included ethnographic data (stories and direct quotes) which showed the realities of these young peoples' lives. As a result of the work of our pilot project, and nine others, services were funded Australia-wide with a broader definition of 'family reconnection' than 'returning home'. We had successfully given these young people a

chance to be heard and to shape future service provision. In this circumstance stories clearly served the interests of our clients.

As this example shows, in social work, research directly informs practice, and the outcomes can be concrete. Tuffrey-Wijne, Bernal and Hollins (2008) define 'ethical research' as that which does no harm; my experience is that social research also has a social justice component. It is conducted not only to identify service gaps or situations for the disadvantaged, but also to remedy these circumstances. There are, of course, limitations (funding, government responsiveness and so on) so when discussing research goals with clients I was always careful not to make broad promises. I used to joke with families that I didn't have a magic wand. Yet as a writer I do, especially as my young adult novel dwells on the border between fantasy and magical realism. Unlike social work practice, however, the outcomes are not 'real world' in fiction, so where are the ethical harms? This was the first question I needed to explore in reconciling my social work and writerly practice.

### **Ethical narratives**

Within qualitative paradigms, I align with Smythe and Murray's view that ethics should be more reflexive than procedural, and that 'ethical issues in narrative research are best rendered in shades of grey rather than in black and white' (2000: 328). Stories, and the narrative impulse underpinning them, allow us to explore the 'grey' areas, particularly as they relate to identity. In fact, according to Polkinghorne (1988), our narratives are our identities. Specifically, narratives aid enculturation, teaching us who we are, our place in the world, how to behave, and even what to believe and why (Le Guin, 2004; Daiute & Lightfoot, 2004; Clandinin & Connelly, 2000; Sarbin, 2004; Nelson, 2004; Parry & Doan, 1994). Narratives can bring to the fore previously invisible stories of the 'special', deviant and other (Muncey, 2010).

Yet while there is support for the idea that stories are influential in representing or even forming identity, the role of the author in achieving influence in this regard is more contentious due to epistemological questions around who creates meaning in a text. However, as Booth argues, every text is a result of authorial choices (2005: 77). This is not just about technical skill. Cosgrove suggests novels evoke an empathic response which can create awareness and even bring about changes in attitudes and behaviour towards others (2006: 135). Eisner agrees, noting that this requires art makers to not only be skilled at their medium, but to hold a sensitivity towards what they're trying to depict (2008: 11). That is, it is partly the writer's response to the world that enables empathic resonance to occur in the reader. This argues then, that even fiction can have 'real world' outcomes.

As a writer I take this to imply a level of responsibility for my creation and the impact it may have – an ethical imperative. But the 'real-world' impact could go further. The words of Le Guin (2004) resonate with my social-justice world view when she says the writer has an obligation:

by offering an imagined but persuasive alternative reality, to dislodge my mind, and so the reader's mind, from the lazy, timorous habit of thinking that the way we live now is the only way people can live. It is that inertia that allows the institutions of injustice to continue unquestioned (118).

In the same vein Finley (2008) notes that art can challenge social inequity because it presents diverse ways of living in the world (72). Accepting that even fiction has the power to serve or harm the interests of those about whom it is written creates a desire to approach my storytelling with the same ethical care I would take towards my social-work clients; a desire which has transformed my project.

### **The interests of the story or the interests of the characters?**

On reflection my project has always been a hybrid of my social work and writerly ontologies. Yet only when I spoke with the astute CEO did the two clash. As a social-work student on placement years ago, I worked with teenagers with Cystic Fibrosis. Two things struck me: they were very creative, and they had an ethereal quality to them. I remember my supervisor saying CF children are often very attractive. Of course, my writerly brain began to imagine and associate, noting how these characteristics were fairy-like. Years later, I read an article about people with Williams Syndrome which suggested their unusual facial features might have inspired descriptions of pixies in folktales (Lenhoff et al, 1997). That fitted neatly with the slowly gestating idea of a novel in which disabled teenagers evolve into mythical creatures like fairies or pixies. The notion of transforming the characters served the interests of a 'fantastical' story.

Still later, when accepted to university to write this novel, I underwent the rigorous university ethics process that focuses attention on the treatment of the vulnerable. Then I met the astute CEO, and faced the possibility that transforming an illness or disability through magic could be problematical. Further, the families of teenagers with Williams Syndrome expressed concern that the article I had read romanticised the condition. I questioned whether I should write about these conditions at all. What harms or goods could arise from writing disabled characters in the fantasy genre? If the disabilities served the interests of the story would this increase the risk of harm?

I saw an immediate obvious good around increasing public awareness. This aim, expressed in my ethics proposal and instruments, married with the missions of both organisations that I wished to meet with. Mark Haddon's (2004) book, *The curious incident of the dog in the night time*, is cited as a novel that achieved increased awareness, in this case about Asperger's Syndrome. But not all critics concurred: Allbery (2003) noted that while the character's unique perspective made the book work he questioned whether it truly represented an autistic way of thinking. Online reviewer Chen, himself autistic, bluntly stated that if you wanted to understand autism, the book would not help (undated blog).

In defense, Haddon argued that he had written about difference, never labelling his protagonist's condition because labels don't help us understand others (online blog, 2009). The implication was that it was the media who used the Asperger's label, and therefore he could sidestep any accusation of ethical wrongdoing. He also claimed not to have researched Aspergers, yet I discovered that he had previously worked with children with autism. Bearing in mind the autoethnographic methodology of this essay, as a researcher I felt this background would have informed the creation of his central character. It highlighted for me how 'awareness raising' could increase the reader's understanding of the *writer's* understanding, which may or may not be

accurate – a potentially harmful outcome. Neilsen suggests this is really all that is possible, because fiction is never about speaking for another but speaking from our own experience (2008: 97). Yet my social-work ontology included a belief that the story could serve the client. Ethically, I wanted to avoid trivialising serious conditions by rendering them inaccurately for entertainment purposes. Yet as a writer I wanted to create an entertaining novel. Clearly these two ways of thinking were in conflict.

Continuing my exploration, I noted Banks' argument that even if it's not possible to tell the whole truth (because we can never truly capture another's experience) it is not okay to lie (2008: 160). Creating misunderstandings is not quite lying, but it is misrepresentation. One could argue that increasing awareness of a disability or illness *at all* is still a step in the right direction, since the absence of stories can cause harm, rendering minority groups invisible. Tuffrey-Wijne et al note that it can be unethical *not* to undertake research on those with disabilities because then their voice and experience will be disregarded (2008: 188). But the risks of misrepresentation are real: Couser, in reviewing the memoir *Lying*, by Lauren Slater, argues that Slater not only remystified the long stigmatised condition of epilepsy, but by placing herself as an authoritative voice, as psychologist and possible epileptic, potentially perpetuated harm to the entire epileptic community (2005: 152). This is a compelling argument for writing about a condition as truthfully as possible. This conclusion led me to a new dilemma.

### **Responding to writerly dilemmas**

I now recognised the importance of writing a properly informed novel, but I was also aware that as an unpublished novelist my ability to increase awareness was potentially very limited. As a social worker, I knew my reports were being read at the Federal level and used to guide policy decisions. But my novel may never be published, or may have a small print run. On one level I am also writing this novel for personal reasons; it is a story I want to tell.

Meeting the families of those with Williams Syndrome therefore felt somewhat vampiric, as there was little I could offer in return for their time and trust. Yet if I didn't spend time with them, I would most certainly write a less truthful depiction. I was reassured by Behar, who notes that in ethnographic research the only way to accomplish anything is through the generosity of those who share their stories, and such sharing can't be repaid (2008: 534). Yet I still wanted to 'get it right', to not glamorise their situation or 'steal' aspects of who they are: essentially to behave ethically with what I learned and saw. I realised that in this situation my social-justice imperative to make a difference in the real world was limited by the realities of a writers' scope, and this helped me to accept the situation. I was doing my ethical best, even if it did not meet with the applied ethics of social-work practice.

I still faced the dilemma posed by the astute CEO, which I now saw, essentially, as whether to place first the interests of the people I'd met, or the interests of the story. I began to reflect on my novel's genre. In fantasy fiction there is an implicit contract with the reader that there will be some sort of escape from the boundaries of reality (Swinfen, 1984: 6). Jackson (1995: 9) goes so far as to argue that the desire to transgress the natural order is at the core of fantasy. But dealing with real

organisations and real people I was forced to question whether it was fair for magic to take me away from reality.

As noted, the original concept of the novel was to transform disabled young people into mythical creatures, to effectively ‘magic away’ the negative aspects of their conditions, like decreased life expectancy, numerous hospitalisations and discrimination. On reflection, I saw that such a rosy presentation could perpetuate the ‘transcendent’ meta-narrative prevalent around those who suffer, a meta-narrative which effectively wipes away reference to the pain and struggle they experience, outlined in Carney’s paper on survivors of the Holocaust (2004: 202).

My reflections on this dilemma incorporated my own life experiences around disability, and thoughts about a conversation I had with a relative of one of the Williams Syndrome teens. We agreed that what is labelled as ‘different’ and therefore ‘not normal’ might be more constructively framed as different, but equally valid, ways of perceiving and relating to the world. This led me to the idea that rather than creating a physical transformation, the ‘magic’ of the novel might come from exaggerating the differences in the way the characters experienced the world to the point where their way of seeing and acting could be *perceived* by others as magical. In this essentially postmodern approach the characters metamorphose in the readers’ mind according to the label they are given, whether ‘fairy’ or ‘pixie’ or ‘disabled’. Yet they are actually the same as they had always been: they shift according to who is doing the viewing. I found support for this approach in Echevarria’s definition of ontological magical realism as writing where the magic stems from the vision of the observer (Faris, 1995: 165).

As an example, the following extract shows how Vivi, a fourteen year old with Williams Syndrome, relates to the world. Those with Williams Syndrome often have a strong connection with music. Vivi’s aural senses make sense to her, but to an outsider, her understanding of others might seem supernatural.

The music’s got louder since I was in hospital. I don’t think I used to hear it at all, one time, but then I heard it, and then it got closer and closer. Now it’s there all the time. But it’s not bad. I like it. And it’s helpful. Usually I don’t really understand people. They don’t say what they mean, and it’s hard to work out what they do mean. But now, I can listen to the music, and that tells me more than their words ever do – if they’re sad or happy or anything.

Kalia has the most beautiful music I ever heard. I couldn’t hear it properly in the hospital, because of all the hospital noise, and because she was sick. Her music wasn’t right. Like the notes had got shaken up and landed in the wrong place. Or they were backwards. Or something. Just wrong. But here in the garden, with the sunlight singing and the bees humming and the flowers whispering, her song was clear and strong. It had a jaggedness underneath, but very faint. That meant she was a bit upset, but mostly happy (extract, Le Rossignol, 2011).

Shifting genres makes the ‘magic’ less fantastical and obvious; more ambiguous. Is magic real, or is it a way of seeing that is outside our usual realm of perception? At this point I realised that after years of planning my novel along the familiar path of fantasy, I had wandered onto the twisting path of magical realism. I was a little afraid

of where it might lead. Fantasy offers a safety valve because magic can serve as a useful wish-fulfilment tool. By shifting to magical realism, I was removing any easy way to solve problems. As Faris notes, in magical realism the world is depicted as realistically as possible, and the magic emerges from the real almost without us noticing (1995: 174). This reality-bound approach committed me to showing the downside of the characters' conditions as realistically possible. They could not avoid the negative realities – their disability would no longer be magicked away.

### **Towards concluding**

By now I felt I had resolved my ethical dilemmas, and reconciled my social-work ethics with my writerly practice, if not perfectly, then at least comfortably. Returning to my social-worker toolbox, I noticed two things that informed this process. The first was the ability to reflect on my practice, placing the interests of the groups I wanted to write about beside the interests of the story, and questioning whether I could serve both. Banks affirms that self-reflexive practice is critical if fiction is to have validity as an ethnographic tool (2008: 157). Moving away from my original concept to a grittier, more realistic novel, I hope I can honour the stories of those I've met and increase awareness about disability without buying into metanarratives about 'specialness'.

An unexpected consequence of this reflexive process was that I found my ontological home in magical realism, where a sense of wonder can sit side by side with a desire for social justice. Further, I was able to sit with my discomfort about speaking others' identities once I realised that magical realism:

is a means for writers coming from the privileged centers of literature to dissociate themselves from their own discourses of power, and to speak on behalf of the ex-centric and un-privileged (D'Haen, 1995: 195).

The second factor was my training as a Narrative Therapist, which tells me we can rewrite the stories of our lives and come to a different understanding of who we are as a result of how we frame our experiences. Too often it is cultural stories that define our self-view, and when people realise these are not fixed, they can explore other ways of being (White, 1991). The novel shifts between the points of view of several characters, which allows me to play with ideas about identity and labels.

Looking back, I realise I actually concur with Mark Haddon as I aim, through taking on another's voice, to encourage my readers to connect with different ways of seeing the world. This is where my social-work thinking and my writer thinking diverge. Although my commitment to social justice compels me to give voice to the unheard, as a social worker I question my right to assume another's voice. Yet as a novelist I am reassured by these words:

Arts encourage a transcendent capacity. They allow the creator and the viewer to imagine possible ways of being, encourage the individual to move personal boundaries, and challenge resistance to change and growth (Higgs, 2008: 352).

In the end the reconciliation between social-work ethics and writerly practice is not a completely comfortable fit. But Finley notes that art is created by the tension between

artistic integrity and truthfulness, and suggests there is a space between the epistemological viewpoints of artists and social scientists where new understandings and practices emerge (2008: 72). I think *values* lie in that space, and have the power to bridge the divide between knowing and doing. At the core of my values is my commitment to having the story serve the interests of the subjects, but during my journey towards reconciling my social-work ontology and my writerly ontology I have found that the choices I make as a writer are fluid, and that because of my guiding values I can make choices which allow me to serve the interests of both story and subject.

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