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Paediatric pathographies: Reflecting on childhood illness narratives

Abstract:

Pathographies (written illness memoirs) are not just a telling of signs and symptoms but social stories of the embodiment of illness into a life trajectory. It is through the 'engine of narrative' that writers make meaning of their particular experience of illness, and their journey to reconstruct a disrupted life trajectory. Written illness memoirs help to build dynamic perspectives about illness and its presentation.

But storytelling and story writing requires a physical and cognitive skill level not always available to the person with the story. Paediatric pathographies, the illness narratives of children, are restricted by a social voicelessness. Published paediatric pathographies tend to have been told by others, or by adults remembering the past, and explore lives that have often had illness present from a very young age. How does the writer of a paediatric pathography structure their narrative compared to those who compose adult-onset illness narratives?

Two pathographies (Lucy Grealy's *Autobiography of a face* and Brent Runyon's *The burn journals*) will be discussed in this paper through the framework of the lived illness experience and its impact on the lifeworld of the authors. Both are pathographies written by adults narrating their stories of childhood illness experience.

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Keywords:

Illness narratives – Memoir – Paediatric pathographies

Not only are we born into complex communal narratives, we also experience, understand and order our lives as stories that we are living out. Whatever human rationality consists in, it is certainly tied up with narrative structure and the quest for narrative unity. (Mark Johnson 1987: 171-172)

We live in a world where stories surround us and are within us, assisting in the exploration of our experiences. We share stories and hear them from others. We create a narrative sense of self from the stories we tell ourselves, and tell others about ourselves. Narrative – in its most broad definition – can make a meaningful pattern out of events that otherwise seem random. When lives are disrupted by the onset and ongoing nature of chronic illness, illness narratives emerge from a need to examine the chaos, searching it for insight and meaning.

Illness narratives, also known as illness memoirs, are a subgenre of autobiography publications. Amanda Nettelbeck states that the interest in writing about stories of illness is based upon the often devastating impact a sudden significant illness has on an individual's sense of self and their projected lives (Amanda Nettelbeck 2008). Writing an illness memoir offers a chance for self-reflection and reflexivity, an exploration of memory and what is held as 'truth' (Philip Neilson 2013) – a rewriting of the self, as Mark Freeman writes, as 'oneself is figured anew through interpretation' (Mark Freeman 1993: 3). "Illness memoir has become an area of writing that interests the general public and those working in health and wellbeing industries, particularly when the memoir achieves an impression of authenticity and quality, and particularly as the voice of the ill person tells a story that reflects cultural constructions of illness and disease. Illness memoir has become an area of writing which, when integrated with authenticity and quality, interests the general public and those working in health and wellbeing industries, particularly as the voice of the ill person tells a story that reflects cultural constructions of illness and disease.

But what of the illness narratives of children? In a society where ill children's voices are not routinely recorded or published, child illness memoirs form a very small cohort within the burgeoning number of stories about adults' experiences of illness. Of this number, most are the recollections of the now-adult, or of the child's carer (including the health professional).

How and why illness memoirs are written is the central discussion of this paper. Adult-onset chronic illness is often expressed as a 'biographical disruption' (Michael Bury 1982), but childhood-onset illness can occur before the strong positioning of the child within their lifeworld has occurred. It acts as an influence on a potential but not yet established life trajectory. In this paper, I will the composition of two childhood-onset illness narratives written by adult authors will be compared to the typical narrative framework of adult-onset illness memoirs.

What it is to be ill

In 1930, Virginia Woolf, plagued by persistent ill health, published the essay 'On being ill' in which she queries why illness is not regarded an important subject for writers. She blames a 'poverty of language' with which to express the 'daily drama of the body', and the need for the writer to look things 'squarely in the face' with the 'courage of a lion tamer'. In this landmark essay, itself revised and republished over several years, Woolf writes about how illness reveals and exposes parts of the self that have been hidden, the 'undiscovered countries... disclosed' and the 'ancient and obdurate oaks... uprooted in us by the act of sickness' (Virginia Woolf 1948). She was, it seems, referring to the consequences of illness and its imposition on normal life as well as the effects of disease symptoms.

The discourse around illness memoir has a foundation in the concept of *illness* as a social construct (Phil Brown 1995). The late-modern understanding of illness - particularly that of chronic or ongoing illness - is influenced by societal and cultural connections as much as the actual experience of the disease. This has been a historical shift from early science-based medical viewpoints about what constitutes a person's account of ill health. To many, including increasing numbers of health professionals, *disease* has a more singular meaning than that of illness. Disease has been defined as the biological condition (Peter Conrad and Kristin K. Barker 2010), a clinician's view of signs and symptoms (Arthur Kleinman 1988), a set of presenting factors that help guide health professionals towards a possible diagnosis and treatment pathway. During the rise of the biomedical model of medicine, particularly through the nineteenth and twentieth centuries, disease became separated from the person and therefore from the experience of having the condition (Mike Bury 2001). Illness is that lived, individually-interpreted experience of disease, the 'innately human experience of symptoms and suffering' (Arthur Kleinman 1988: 3), the darker side of life which will inevitably be experienced by everyone. As Susan Sontag writes:

Illness is the night-side of life, a more onerous citizenship. Everyone 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. (Susan Sontag 1978: 3)

Neurologist Oliver Sacks writes of ill health as not simply a physical or functional disturbance but one that is shaped by a person's identity (Andrew John Hull 2013) and, in turn, often contributes to the reshaping of ideas of self. Extending this, Arthur Kleinman (1988) considers illness as a representation beyond the individual, 'to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability' (p3), framing illness as an interdependent event. In many illness memoirs, this reflection on personal or family identity becomes the main subject of the manuscript, offering what Philip Neilson calls a 'through-line' to shape the story.

Reclaiming the voice: personal illness narratives

The history of illness memoir has been said to align itself with the development of biomedicine in the modern world (Mike Bury 2001). In the eighteenth century, the physician had little to offer his patient in the way of care except for an understanding of the ongoing narrative of being unwell and its social interpretation. Voltaire (1694-1778) reportedly wrote that ‘the art of medicine consists of amusing the patient while nature cures the disease’.

With the development of the hospital and the medical laboratory in the .century, more sophisticated investigative and treatment options focused on the signs and symptoms of disease and less so on the experiences of the patient. By the twentieth century, the medical profession had the authoritative voice over what were considered the fundamental elements of disease and treatment options, stripping the voice (and the experience) of the patient from the illness (Mike Bury 2001). Now, as the twenty-first century unravels, the importance of the patient’s story is re-emerging as a significant component of health professional-patient encounters (Alan Bleakley and John Bligh 2008): listening and understanding the effect of illness experience aids health professionals in the ability to assist their patients. Michael Holroyd’s subtle essay ‘Illness in England’ expresses the issues that arise when a patient’s story isn’t heard:

‘(My operation) was a complete success. My surgeon announced this the next day and confirmed in a month later when I called on him in his consulting room. It was true that I couldn’t walk...but technically, it was a beautiful job.’ (Michael Holroyd 2002: 318)

The reported surge in publication of illness memoir in the last fifty years indicates a change in the agency of the unwell person, with a need to present their life embodied with illness, particularly in the face of unsatisfactory encounters (such as Holroyd’s) with health professionals and health systems. It has also been recognised as a methodological shift towards language and narrative as a way of understanding ‘our social world and its constitutive relation to identity’ (Anne Whitehead 2014: 112).

Many regard illness narratives as the reclamation of an individual’s own story through the telling of the experience, shaping it into a cohesive order and being witnessed as a storyteller (Arthur Kleinman 1988, Arthur W. Frank 1995: 7 , Anne Hunsaker Hawkins 1999). Frank argues that people with serious illness ‘are wounded not just in body but in voice’ (p. xii) and that storytelling recovers the voice often lost in the process of having the illness. As illness is embedded into a person’s life trajectory, the illness narrative is told not *about* the body, but *through* it: a lens through which embodied illness experiences are primary and not relegated to the sidelines. Anne Hunsaker Hawkins emphasises that although pathography tells the story of illness, many texts also include information and anecdotes from before the person became sick (Anne Hunsaker Hawkins 1999: xviii). This knowledge assists in establishing the person’s pre-illness identity and their social environment. It also shows the reader the ‘larger story’ of a person’s life, in which the illness is not the only entity but is embedded within the ‘joys and sorrows, the banalities and dramas that constitute the process of living’ (Neil Vickers 2012: 1071).

Authors of pathographies often discuss how the writing of their illness narrative helped them to re-navigate their world, assisting them in drawing a new map to reach their destination (Arthur W. Frank 1995: 1). Pathographies can be expressed as journeys of healing or of sense-making, a type of survival story that can resemble accounts of political, racial or social struggle (Anne Hunsaker Hawkins 1999: 2). They are stories that speak of a violent interruption to the normal life trajectory, of having worlds collapse, chaos reign; but they also speak of re-orientation, understanding and transformation.

Paediatric pathographies: the silenced voice revisited

Illness narratives and witnessed storytelling give voice to ‘what once was inarticulate’ (Sayantani DasGupta 2007: e1387) with the assumption that the person with the story *regains* the ability to be heard. Stories from children with chronic illness, however, remain quiet for reasons largely attributable to the physical and cognitive developmental limitations of the storyteller during the time of the illness event. It is argued that, as the experience of chronic illness is often interdependent on relationships (Arthur W. Frank 1995, Sayantani DasGupta 2007), paediatric pathographies can be genuinely articulated by people close to the child during its illness. They can also be expressed by adults remembering their childhood, acknowledging Mark Freeman’s point that memory and therefore ‘truth’ are interpretative acts (Mark Freeman 1993: 29).

The pathographies discussed in this paper - Lucy Grealy’s *Autobiography of a face* (Lucy Grealy 2003) and Brent Runyon’s *The burn journals* (Brett Runyon 2004) - give voices to children with childhood illnesses, albeit retrospectively, through the recollections and reflections of the now-adult. The narrative structure departs from the framework of adult-illness narratives, which emphasises re-formation and re-orientation. Instead, these memoirs focus on identity formation and a negotiation of life’s pathways.

Autobiography of a face

Lucy Grealy was nine years old when she was diagnosed with Ewing’s sarcoma, a type of cancer more common in children than adults, and she was thirty-one years old when the book about her life was published. Grealy’s early diagnosis placed her in a position where illness and its consequences were nearly always part of her life trajectory, and formed an early framework for how she had to live.

Autobiography of a face was not written to be a chronological account of Grealy’s illness. Although she spent five years undergoing treatment for cancer, and a further decade or more having over thirty reconstructive surgeries on her face, Grealy was more concerned that her book be considered a literary contribution from a serious writer (Anne Patchett 2003). The focus of the pathography is very much on the influence on her social and cognitive development of being ‘ugly’ – that is, her physical facial disfigurement and its constantly changing manifestations. The many changes to her face, from the acute effects of surgery to the slow tissue disintegration

of her jaw and teeth, influence the dynamics of her identity construction. In the beginning, she understands little of the impact of her cancer and its lasting scars:

I was still blissfully unaware, somehow believing that the only reason people stared at me was because my hair was still growing in (after chemotherapy) (Lucy Grealy 2003: 6).

In time, her facial disfigurement became the crux of every encounter in her lifeworld:

This singularity of meaning – I was my face, I was ugliness – though sometimes unbearable, also offered a possible point of escape. It became the launching pad from which to lift off, the one immediately recognizable place to point to when asked what was wrong with my life (Lucy Grealy 2003: 7).

Throughout the text, Grealy fluctuates in her reaction to her face – she is sometimes reflective, sometimes anguished, even as she moves into adulthood. She identifies herself as ‘an interesting case’, as someone who ‘knew my face had an effect on other people that I could sometimes use to my advantage’ (p.104). Although she purports to have ‘a strong sense of myself’ (p.105), there are times when the realisation that others see her differently to how she sees herself makes her feel meek and vulnerable.

The constantly changing nature of her disfigurement does not allow her to settle on any one image of herself. Looking back at a childhood photo, she states ‘I don’t look anywhere near as repulsive as I then believed I did’ (p.13), but acknowledges that the taunts of others, especially during her school years, felt vindicated:

I was ugly, so people were going to make fun of me: I thought it was their right to do so simply because I *was* so ugly, so I’d better get used to it (Lucy Grealy 2003: 145).

She variously disdains femininity, feeling a sense of power from remaining removed from dressing like a woman, and tries to embrace it by ‘collecting lovers’ (p.207).

The pathography’s denouement recounts more rounds of surgery – twelve operations within three years – to which Grealy finally reacts by refusing to look at herself in the mirror or any reflective surface. She comes ‘back to her face’ with effort:

The journey back to my face was a long one...Unlike some stroke victims, who are physically unable to name the person in the mirror as themselves, my trick of the eye was the result of my lifelong refusal to learn *how* to name the person in the mirror. My face had been changing for so long that

I had never had time to become acquainted with it, to develop anything other than an ephemeral relationship with it (Lucy Grealy 2003: 221).

Autobiography of a face is a reflexive and a reflective work. As this memoir presents it, the disruption to Grealy's life is not so much the illness itself, but adolescence, and her exposure to normative frameworks that she is unable to enact because of her ongoing medical treatments. Finding an identity that isn't related to her face proves to be a difficult task, and one that is unresolved by the end of the text, although there is a 'great revelation' that most people live life by pretending, and 'leave our original faces behind to turn in to ghosts that will inevitably resent and haunt us' (p. 22).

Lucy Grealy died of a heroin overdose in New York in 2002, at the age of thirty-nine. Her illness narrative is extended in the afterword to the 2003 edition of her book, written by close friend Anne Patchett:

Many people have asked me if she died of cancer, and even though she had been free of cancer since she was ten, there is a sense in which that disease and its aftermath were a large part of what killed her. She continued to struggle all her life with the issues she wrote about here: reconstructive surgeries, loneliness, and the pain of feeling different. (Anne Patchett 2003: 227)

The body of the book, however, remains as a representation of a search for identity while living with an established chronic illness.

The burn journals

Brent Runyon was fifteen years old when he pulled on a dressing gown soaked in petrol and set himself alight. He had burns to eighty-five per cent of his body and spent a year in acute hospital and rehabilitation centres. Runyon took four years to write *The burn journals*, starting a decade after his suicide attempt. The pathography retraces the sequence of events from a short time before his self-immolation to his return to high school twelve months later.

Much of the narrative is a chronological account of his burns treatment and physical recovery, with milestones linked to the pain and progress of his wounds:

Today's the day I take a bath. They're going to put me on a stretcher and wheel me into the bathroom and use some sort of contraption to lower me into the not-too-hot water. It'll be so much better than the other way we do burn care. No wiping every wound three times and screaming (Brett Runyon 2004: 52).

When reporting the initial stages of his burns treatment, Runyon's narrative is structurally fragmented. Accounts of treatment and surgery, and interactions with his

family and the health professionals around him, are short segments that have limited continuity, reflecting his physiological states of un/consciousness. As recovery progresses, the narrative gains continuity and becomes a steady account of physical healing.

In itself, Runyon's book is a chronic illness story of physical and social recovery from trauma. Underlying this, however, is the narrative of his primary chronic illness – his depression. Within the text, particularly in the first chapter, there are brief reports of his depressive symptoms, self-harm behaviour and previous suicide attempts; beyond that, however, his mental health remains largely unexplored. Runyon is dismissive in his account of the psychological counselling he received during his hospital and outpatient periods:

I hate Dr Rubinstein. My problems aren't anything to do with her. I don't even have any problems, now that I think about it. I'm happy and I've got friends and family and they understand me and I don't need her to understand me or to ask me questions and I wish she'd just leave me the fuck alone (Brett Runyon 2004: 51).

Later in the book he reports on a session in which his psychologist tries for engagement:

“Hi, Brent. I'm Mark Nusbaum, you can call me Dr. Nusbaum.” Another Mark, another mustache... Anyway, it's about time for this fucking therapy session to be over. Jesus, what do I have to do to get out of here?

“Are we done yet?”

“Yes, we're done. Nice to meet you.”

“Yeah, likewise.” God, I hate psychologists. I hope I don't have to see him again (Brett Runyon 2004: 242).

Runyon reports on the process of writing the first draft of *The burn journals* in the afterward to the 2005 Vintage Random House edition:

I managed only a small number of words a day – five hundred or so – but after a year of writing every day, I had more than enough pages to fill a book, and I had the story of that year of my life, written in short brutal bursts that I couldn't bear to read. (Brett Runyon 2004: 321)

Re-visiting the experience was an attempt, says Runyon, to be ‘done with the whole burn thing, forever’ (p. 5), however this quest for closure was not realised because ‘the burn thing’ was not the full illness narrative. Runyon acknowledges that writing his pathography was not the catharsis he had hoped for as it did little to address the reason underpinning his suicide attempt:

I guess I was hoping that writing all of this stuff down would somehow clear my brain and I would live happily ever after, or something. But two years after I finished writing, around the twelfth anniversary of setting myself on fire, I slipped into a serious depression... Death, once again, began to seem like the perfect alternative to the joyless world of depression. (Brett Runyon 2004: 323)

This short afterword in the later edition of the book extends Runyon’s pathography into adulthood and into a state of reflection that appears linked to the publication of his book. The public acknowledgement of his text resulted in Runyon meeting many people with their own illness narratives, creating a reader’s community that assisted Runyon in his quest:

As I talked to more people, I realised that the only thing unique about my story is the rather unfortunate and dramatic way in which I tried to kill myself. Other than that, I’m just another guy with a history of depression, which is something very comforting to me (Brett Runyon 2004: 324).

The burn journals is the chronological reporting of a traumatic event caused by Brent Runyon’s primary chronic illness. The glimpses of his pre-trauma life reveal an adolescent already living with depression. At the end of the book, his depression remains untreated and is without change. The afterword gives an account of Runyon’s ongoing illness that, finally, includes the narrative surrounding his depression.

Negotiated life trajectories

The majority of illness narratives, and the main concern of writers such as Frank, Kleinman and Hawkins, are those that give voice to the storyteller who has had to reconstruct their identity, and their relationships, with their illness experiences now embedded into their lifeworld. Hyden adheres to this understanding by supports this in describing narratives as ‘an opportunity to knit together the split ends of time, to construct a new context and to fit the illness disruption into a temporal framework’ (Lars-Christer Hyden 1997: 53). Paediatric pathographies, however, are not necessarily evidence of illness fracturing time. They don’t depict *re*-construction of new maps as described by Frank – the map has been there since very early days. These narratives instead explore the *negotiation* of pathways on a pre-existing map.

Pathway negotiation is particularly relevant in accounts of life trajectories that cannot fit within normative societal and cultural frameworks. Childhood-onset illness

narratives exhibit constant negotiation, particularly if onset is before adolescence. Illness has been described in terms of its disruption to a projected continuity. An illness that occurs early in life creates its own temporality without the experience of 'normality' to disrupt.

Commercially published pathographies about illness in childhood such as *Autobiography of a face* and *The burn journals* are not common, but then they do not sit neatly within the framework of the illness narrative as a journey towards re-establishment of identity on a newly constructed map of life. The story that paediatric pathographies tell is more complex and less able to be represented within the traditional dramatic plot structure that includes a beginning, a middle and an end. Although Hyden suggests that illness narratives have no end (as chronic illness is ongoing) (Lars-Christer Hyden 1997), the reclamation of identity and the reconstruction of voice in adult pathographies assist in shaping these written works to a broad dramatic framework. Unable to be so succinctly framed, authors of paediatric pathographies tell their stories from within a different context and have a primacy of voice that arises from experiencing early-onset illness.

Autobiography of a face is an example of complex writing about living with illness, not as a disruptive extra that causes change, but as an integral part of self. *The burn journals* is a dialogue that focuses on events arising from an illness that remained unexamined. While the former exists as an articulate written voice of its own, the latter required its afterword to extend understanding of the author's primary illness experience. Both are indicative of the dynamic nature of an individual's illness experiences, and how narratives can be vulnerable to change and reinterpretation that is dependent on the story the author tells.

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