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Story in Health and social care

Story in health and social care

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Abstract

This paper offers a brief consideration of how narrative, in the form of people's own stories, potentially figures in health and social care provision as part of the impulse towards patient-centred care. The rise of the epistemological legitimacy of patients' stories is sketched here. The paper draws upon relevant literature and original writing to consider the ways in which stories can mislead as well as illuminate the process of making individual treatment care plans.

Key Words

Story, health and social care,

Introduction

Story-telling is a peculiarly human trait and a practice through which we rehearse, invent and re-invent our humanity (Kearney 2002). Stories are the way in which we constitute ourselves and make a meaningful identity in relation to others and, as such they are never finished and always open to revision. Furthermore, stories are the way in which we routinely make assessments, ethical and otherwise[i].

In times of trouble and in the face of suffering, people need to tell stories about their situation as a matter of urgent necessity. The distress and pain of illness and injury, like other forms of suffering, engenders the need to tell stories, to make sense of what has happened for oneself and for others (Frank 1995).

Medicine, in its response to human suffering, deals with stories, both as a form of evidence and as a method whereby evidence is evaluated. The status of patients' stories as part of the evidence for diagnosis and decision-making about treatment and care plans has risen and fallen. This paper sketches out some of the circumstances around narrative (re-)emerging as a valued form of knowledge and the development of an apparent imperative to attend to patients' stories in health and social care settings. This paper asks whether patient narratives have a place in the 'management' of health and social care decision-making and, if so, whether they can be interrogated as evidence, or have to be accepted as a process. It goes on to question the place, impact and value of narrative in the exchange between professional and patient and to problematise some of the emergent orthodoxies of patient narratives. All of the authors use stories in their own practice, so drawn upon this experience, as well as the

original work written for this paper in seeking to formulate questions that could inform the future practice of health and social care workers.

Medical stories

Stories are a particular form of the more general category 'narrative': narratives may be fragmentary and partial, whereas stories tend to be shaped so as to have a beginning, middle and end. Health and social care professionals' practice relies on patients' stories of their suffering as part of the process of diagnosis and deciding on appropriate treatment. However, one version of the history of medicine tells how the rise of biotechnologically informed modern medicine, with its totemic effective interventions, has meant that patients and the stories that they tell have been lost from view (Illich 1976, Salter 2004). While historically medical men had to attend to patient narratives, with diagnosticians taking patients' accounts of their symptoms seriously in the analysis of causes of and treatments for disease, this attention has diminished as other forms of evidence have taken precedence (Porter 1997).

As the status of medicine as a profession has increased, the weight attached to medical evidence has grown concomitantly at the expense of patients' stories about their own state of health or illness. Research into medical talk shows how patient's evidence can be readily dismissed where it appears to contradict medical data (Strong 1979, Oakley 1980). There is no suggestion that medical professionals intend to disregard patients' narratives or to deem them inadmissible to clinical decision-making, particularly given that medical students continue to be taught to listen to their patients. Rather, the epistemology of epidemiologically-informed, statistically significant evidence that underpins the interpretation of results from tests and assays trumps the nature of patients' stories as a form of knowledge at almost every turn. Patients' feeling that their own accounts of the experience of their suffering are not given due weight can have the effect of compounding distress and anxiety. This point is made eloquently in written accounts of people suffering a serious disease in which health professionals will not or cannot listen to patients' accounts of their suffering and therefore deny its import (e.g. Aldiss 1999, Sinclair 1998). When this happens to a patient who is also a physician, the anguish is further compounded as he or she recognises the professional response (Greene 1971, Sacks 1986).

A technologically and statistically sophisticated scientific medicine may have become inattentive to patients' stories, but it nonetheless uses the form of 'story' as a means of decision-making. Science offers a method for discerning which evidence is important, but it is through stories that clinical practitioners, like their patients, make sense of and utilise that evidence (Hunter 1991). As Elwyn and Gwyn (1999) put it 'Even the most evidence crazed doctors have to translate their perception of 'biostatistical truths' into accounts that make sense to others.' The development of strict protocols for evidence-based medicine confirms the stories that doctors tell about the causes and cures of disease and disability a special epistemological status.

The power of doctors' stories can be illustrated by the example of disputed anxieties regarding MMR (Mumps, Measles and Rubella) vaccine. The MMR vaccination for children was hypothesised to be linked to developmental disorders and, despite excellent scientific evidence

that denies this link (Demicheli et al 2005), there has been a drop-off in numbers of children being inoculated to the extent that an epidemic of measles has been predicted in some areas. The linking of the vaccination with a disorder was compelling for parents of children who experienced developmental problems after receiving an MMR injection. Together with anxieties about vaccine 'overload' (Hilton et al 2007), the initial medical hypothesis became a powerful story that warned parents away from vaccination, despite the risk of serious infectious disease.

Re-instating Patients' stories

The growing inattention to patients' stories by professionals has not gone un-remarked. As biomedicine has, to some extent, lost its interest in patients and their stories, other types of health workers have responded to people's need to tell the stories of their unhappiness. This can be seen in the popular, widespread and still growing use of complementary and alternative therapies and talk therapies. The use of these alternative therapies is additional to biomedicine as patients find alternative outlets for the need to tell stories about their symptoms and their lives.

While other divisions of the healing professions have been attending to patients' stories, voices within medicine have also been calling for a closer attention to patients' perspectives. Patient-centred, narrative-based, values-based and humanistic approaches are recommended by theoreticians and practitioners to promote patient participation in all levels of organising health and social care. Increased attention to patients' stories in the planning and provision of services has become particularly urgent in Western populations where the burden of disease is chronic and increasingly treated in community rather than clinical settings. Chronic disorders, particularly those contracted at a young age, often make patients experts in their own care, in terms of their use of technology and drug therapy as well as more general aspects of the condition. Patients, in the appropriate circumstance, offer a store of experiential and technical knowledge that can aid health professionals in pursuing their own work. Furthermore, the knowledge explosion, rising educational levels and the development of the internet means that patients' perspectives have the potential to be more informed in terms of medical science than ever before. In addition to their medical knowledge, of course, patients' own experience of their condition is crucial to anticipating whether a care plan is likely to be successful. Where patients are embedded in their own social setting, for instance in primary and community care, the meanings of symptoms and their role in every day life is crucial to determining the best course of treatment (Greenhalgh 1998, Greenhalgh and Hurwitz 1998).

While the power and reach of medical discourse makes it increasingly difficult to identify 'lay' views as distinct from medically informed views, 'lay epidemiology' nonetheless addresses dilemmas and issues that medical science cannot tackle or even admit to (Davison, Frankel and Davey Smith 1992). The onset of disease can provoke questions of order and control: 'Why me? Why now?' (Frank 1995) to which medical science cannot offer answers specific to the individual, whereas lay epidemiology, or stories about illness, can. Davison and colleagues describe the lay theory of 'candidacy' to explain why one individual gets heart disease, whereas his brother or sister, living in similar circumstances, does not (1991). Attending to patient perspectives has been justified in economic terms, since patient participation in decisions may reduce costs for the health

service (Elwyn and Gwyn 1999). Furthermore, telling the story of one's troubles and, crucially, having it witnessed by key professionals, is claimed to have a healing and restorative effect in and of itself, through the creation of meaning (Moerman 2002).

Patients' stories thus offer various possibilities in the planning and provision of health and social care by way of providing better technical information and contextual understanding about specific cases. The telling of one's story may itself offer restorative effects for mind and body and, where suitably attended to in the process of planning care, may increase the chances of success.

Organisational reform to introduce 'user perspectives' in commissioning and managing service provision as well as changes in professionals' style of communication towards 'constructive listening' that carefully attends to talk are the order of the day. 'Concordance' between patient and professional in a regimen of 'patient-centred care' with 'shared decision making' that attends to the 'patient experience' have become mainstream health policies and buzz words, even if the practice does not necessarily reflect the rhetoric.

The imperative to attend to narrative has, in some respects, become a new orthodoxy, bolstered by assumptions that everyone has a story to tell (the confessional age in which misery memoirs continue to be best-sellers) and that story-telling is therapeutic. As with anything that takes on the appearance of orthodoxy, there is a critique. The remainder of this paper explores the problems with deploying patients' stories or narratives in planning health and social care by considering the limits of story.

There are serious attempts to introduce patients' perspectives into health and social care. In promoting the merits of narrative-based medicine there has been a marked tendency to underline the increased information flow towards the professional that this method offers. While this line of reasoning may be politic when seeking to convince over-worked health professionals to adopt yet another new initiative, to present stories as nuggets of evidence requiring de-coding is to seriously under-estimate their value. Similarly, the proposition that attending to patients' stories represents a cost reduction measure may be demonstrable, but is partial. If the proposition is that stories are what makes us human, then their intervention in a health care setting should, ideally, un-do some of the more brutal and dehumanising aspects of being a 'patient'. However, if patients' stories are incorporated into health and social care as a means of increasing the information flow towards the professionals and/or to reduce costs and increase patient compliance, the methods of dehumanising have simply been sharpened. Lay perspectives have incorporated medical understandings of disease to a great extent: to what extent can the biomedical evidence base and the process of decision-making about care attend to non-medical stories?

The limits of stories

The danger of tokenism, whereby treatment and care plans attend to the patient's story once the main decisions have been made, is real given the enormous complexity of stories as bearers of identity and ethical value, as well as conveying information and opinion. As practitioners, all three of the authors regularly use story-telling and find it

invaluable. The use of story as a method, process and as substantive material for teaching and care work goes against other orthodoxies and offers people a novel means of expressing themselves in professional contexts. This can be particularly important for people who have not been able to formulate a story, or to have it heard, through other methods or in other forms. The enormous power of story as a complex and nuanced means of expressing our humanity, especially in times of suffering, means that we also need to be aware of its limits. As an oblique means of thinking about this problem, we now turn to considering the moments where stories are not a possible or a preferable means of representing experience. Are there times when a person cannot and should not tell a story, or when a person's story should not be attended to in health and social care settings?

Perhaps it goes without saying that patients sometimes have no interest in the story of their illness being part of the health care process. We consult professionals for a variety of reasons, and these include wanting an assessment of symptoms to lead to an intervention based on medical evidence which the medic has evaluated drawing on experience and knowledge. A patient may wish his or her subjective experience to remain entirely beyond the treatment process because these are aspects of the illness that are dealt with elsewhere, with other people.

Stories that cannot be told

If patient narratives are given weight in decision-making processes, then we must be concerned for those who cannot or will not tell their stories. If story-telling is a feature of humanity, what of the people who cannot tell a story? Does this make them less than human? The tendency to disregard the truth of accounts of people with serious learning disabilities or with severe and enduring mental illness is documented (Goodley, 1996, Gillman et al 1997). People's stories may be disrupted, as in the experience of Alzheimer's (Burke 2008) or Schizophrenia (Predergast 2008) or any other condition that fluctuates or is unpredictable. An absent story or a highly fragmented story which is unshaped or not fashioned into a satisfying expression of suffering potentially allows others to construct compelling stories of that person's experience. Of course, in an under-resourced system, the absence of a compelling story may equally allow patient's needs to be over-looked.

Stories that should not be told

Re-telling one's story may not necessarily be a healing process. If the source of one's illness is a traumatic event that does not make sense because it is, by nature chaotic then revisiting the chaos may compound the injury rather than re-make the self. Stein et al (2007) in reviewing the literature on Post Traumatic Stress Disorder (PTSD), cite Rose et al (2002) to note that debriefing following stressful events can be counter productive in reducing the symptoms of PTSD. Creating and reinforcing narratives that imply the stress reaction is dysfunctional, potentially exacerbates rather than reduces a negative response. This suggests that the context in which a story is told, the interpretive apparatus that surrounds it, is crucial and it is not just the telling, but the witnessing and response to that story that count.

Compelling stories – appropriate responses

Stories are told to give meaning to the apparent randomness of life. Clifford Geertz, the anthropologist, observed that the one thing that humans seem universally unable to accept is the idea that the world may be ultimately deficient in meaning (Scheper-Hughes 2002: 375). But not all meanings are equivalent. Here, again, context is absolutely crucial. The lay epidemiological example of heart disease candidacy (Davison, Frankel and Davey Smith 1992) provides a reason for people's differential experience of disease despite sharing a common environment and genetic inheritance. This explanation makes sense when people see heart disease running in a family, in parallel with mannerisms and temperaments. Describing how a person is like his father and therefore a candidate for heart disease, does not necessarily exclude other explanations for the onset of heart disease, such as smoking, exercise and diet. However, if a story that gives meaning to one's experience is compelling enough, it may have disastrous effects on one's health.

Graham Mort had a compelling explanation for what turned out to be his symptoms of heart disease. He managed to convince himself and his GP that the pain in his chest and shoulder was as a result of being metaphorically infected from reading Nabakov's fiction (see appendix 1). After the shock of an unexpected quadruple by-pass Graham Mort writes that he has not (yet) accepted the disjunct in his own story of himself as a well man.

In suggesting that another story about his diseased heart may emerge Graham Mort implies the multiplicity of stories that can be told about an illness. We offer three stories from the fictionalised case of Miss MacFadyen (see appendix two) who is being transferred from hospital to a care home because her sister cannot cope with her at home. Miss MacFadyen longs to return home, but her sister is deemed too ill to care for her. In a system with limited resources, where the judgement of professionals will be disproportionately powerful, how would such a dilemma be resolved? Whose narrative should be attended to most closely: Miss MacFadyen, who wants to return to her home or her sister who wants her to stay in a care home? Is it true that Mrs Zachery could not cope with the return of her sister or is she lazy and unwilling to share her home? Is Miss MacFadyen placing an unreasonable demand on her sister because her assessment of her own capabilities is hopelessly over-optimistic? To what extent does it help health and social care professionals to have greater access to understanding patients' experience? We can imagine how the competing priorities of these three stories about Miss MacFadyen could be resolved in a care plan, where generous resources and time were available.

Conclusion

We offer no definite answers, frameworks or plans here, only health warnings. We are concerned that a rush to reconfigure care as patient centred will permit the continuation of the trend to treat patient stories as means of gathering clinical evidence and maximising efficiency. We counsel against allowing narrative to become the latest quick-fix dogma, ill defined and therefore primed to fail. We are unsure whether there is a means whereby patients' stories, such as those we include below, can be systematically incorporated into treatment plans. While recognising that stories have much to offer a rich understanding of health and social care, we warn against their adoption as an unqualified good and recommend that their limits be recognised too.

Appendix one: Nabokov and the Angiogram

A new chapter in health fiction.

My story begins in the summer of 2004 on a cricket pitch in North Yorkshire. At the age of 48 years old I'd just bowled 12 continuous overs. The ball was swinging outside off-stump and seaming away – perfect conditions for my style. Six chances were dropped off my bowling through incompetent fielding and, feeling pretty tired, I stalked away to sulk under the chestnut trees on the boundary - where I experienced a distinct pain in my chest.

My first reaction, presciently, was that it was my heart, but within a few minutes the pain had passed away and I went in to bat without incident – except a summary stumping by the preternaturally long-armed wicket keeper. I thought nothing else about it until I experienced similar chest and shoulder pains whilst cycling and playing tennis. My GP referred me to the cardiology unit at my local hospital where I underwent an arduous treadmill test with ECG, followed up by an appointment with a consultant cardiologist.

The cardiologist reviewed my ECG print out and said quite distinctly, ‘Well, there’s nothing wrong with your heart.’ I’d been reading Nabokov’s ‘Lolita’ in which the central character – Humbert Humbert, a near-paedophile – experiences ‘intercostal neuralgia’, a form of referred pain that mimics the symptoms of angina. The consultant listened to this with a tolerant smile and admitted that this was a possible solution to what remained a mysterious set of symptoms. Her words remained with me throughout the next few years as a handy rebuttal to any idea that I might be ill.

I left the hospital, reassured my wife and family, and enjoyed telling the story of the cricket match, the dropped catches, sulking under the trees, and the way that a fictional character from a novel had provided my diagnosis. I’m a writer and teacher of creative writing, so there was a kind of reassurance in this narrative structure. I’d made my symptoms into an amusingly self-deprecating story. I’d given a set of mysterious and alarming symptoms a reassuring narrative form and conclusion. I was active, had a good diet, understood the risks and, as a result of that virtue, fate had dealt me a reprieve.

Five years later, whilst walking across the University campus I experienced a sudden and disabling recurrence of a pain that seemed to spread from my chest into my left shoulder, or from my shoulder into my chest. The pain came again when I was playing cricket, tennis and cycling. A visit to the same GP ensued and I related the original incident – cricket match and Nabokov included. An examination followed and we agreed that I should try physiotherapy for what we both agreed was referred pain from the shoulder area. My local GP practice doesn’t offer an ECG, so the check on my heart function at this stage was purely auditory.

The first questions the physiotherapist asked me were about my heart. I was able to reassure her that my cardiology tests (which I now put at a fictional three years ago, not five, having forgotten the original dates) had proved negative. Months of physiotherapy ensued without much improvement. I continued to play tennis, and to cycle through the pain barrier. My main

symptom at this stage was shoulder pain – I had negligible chest pain, little shortness of breath and none of the other symptoms that might suggest angina.

Upon returning to my GP, an MRI scan was arranged to see whether or not a herniated spinal disc might be referring pain into my shoulder and chest. To a writer, the experience of the MRI scan was fascinating. The way it felt like lying inside a giant tube of toothpaste, the way it is better to keep eyes closed, the way the machine sounded like a pod of hump-backed whales calling, the way any piece of metal in one's body would be dragged gruesomely though and out by magnetic force. It was another good story and possible material for my own writing.

The MRI scan was followed up by a meeting with a neurologist, who was quite puzzled by my symptoms and could find no connection with the routine ageing of my vertebrae and the pain I was now regularly experiencing. She had my medical records to hand and reminded me that my cardiology tests had been held 5 years ago. She suggested that I revisit them. I remember walking away from that appointment, taking tiny steps to the car park, because the pain was now so severe. Denial was by now becoming difficult, even for me, and at least part of me recognised that I was exhibiting classic angina pains.

I immediately booked myself into my GP practice for blood tests and made an appointment with my GP. A weekend of chest pain intervened and I spoke to a senior partner at the practice. No doubt I rehearsed my sporting interests and the fact that my father had lived to be 92 and my mother 87. My older sister had experienced a heart attack, but most of my family – many of them heavy smokers – had died of cancer. The doctor reassured me by saying that, 'It doesn't sound as if this is your heart.' But from that day I began to take low-dose aspirin as a precaution. But the clock was ticking against me.

When I turned up to see my GP, he'd been called away to an emergency. We spoke on the phone later, agreeing that I'd attend the cardiology unit for new tests, 'Don't worry,' he said, 'It doesn't sound as if it's anything to do with your heart. Sometimes we never get the bottom of these things.' I was now more seriously concerned because I'd booked a holiday in France with my partner and son. I chased the hospital appointment after a few days and found out that I'd been lost from the system in the aftermath of a new computer suite being installed. The appointment was re-instated and I went on holiday. The week in France was divided between days when I felt severely restricted by pain and days when I happily walked 6 miles around Paris. Strange and disconcerting.

We returned home on Thursday by which time I was taking phone calls about work on the train. I worked all Friday and Saturday afternoon to catch up with my backlog of work. On Saturday evening I experienced such painful symptoms that I went to A&E at the local hospital – an eighteen mile drive from home. The hospital confirmed that I'd undergone a 'cardiac event' and into the system I went, from cardiac care in one hospital to the cardiac unit in another. I asked a number of doctors whether my original cardiology tests could have missed something – 'unlikely' was the answer.

When I was wheeled into the theatre for an angiogram, I still half believed that the consultants might find nothing – my unsolved mystery – or at the most might have to fit a stent.

Instead, I was told that I had advanced heart disease with all four main arteries compromised. One artery was 90% blocked and surgery was the only solution – if I proved ‘viable’. ‘Don’t worry’ said the consultant, with a smile, ‘you’ll be playing cricket again next year.’ Days of uncertainty ensued until I’d gone through a series of routine tests. A quadruple by-pass was then performed and, at the time of writing, I’m now three months into recovery, walking and cycling again.

When my GP asked me if I’d experienced any psychological effects, I replied that I’d accepted that I might die and had experienced no depression on that account, but that my overriding emotional state was still one of disbelief - for which, I added wryly, there is no prescription. Despite the scars on my chest and leg and the occasional twinges of pain or discomfort, that it still the case. Somewhere deep in my psyche I had refused to make the transition from feeling that I was a fit and competitive man (for my age), to the recognition that I was dangerously ill. The more I recover, the more I deny my sick self and replace him with my risen self.

Such a stubborn psychological condition might be enviable to a hypochondriac. But my state of resistance or denial and my eloquence in spinning a powerful narrative of self had undeniably influenced my GP and delayed my diagnosis. Doctors have their own emotional needs and, at some level, I believe that my GP didn’t want me to be ill either. Through some kind of male intimacy, it was as if I’d infected his judgement with my need to be competitively fit and his need to support that comforting delusion.

Fortunately, I have an ironic self as well as my other selves, and the story I’ve told here – a story of vanity, resistance, near-idiocy, selfishness, denial and delayed revelation – is my new story. It is my refurbished or revised story of a self that acknowledges the wry twists and turns in a plot that now has even more satisfying narrative complexity and structure. I’ve added a few of my wilder morphine-visions and hospital anecdotes too, just to embellish it a little if my audience is willing.

There were few ‘typical’ heart-attack victims in my hospital experience – like many of them I wasn’t grossly overweight, had a good diet, understood the needs for a healthy lifestyle, and exercised regularly. My symptoms were only marginally atypical, so why did I get so dangerously late to arrive at what now seems like a routine diagnosis? There were some systemic failures in the primary healthcare system – particularly lack of routine follow-up to the original cardiology tests. But I also accept that I was complicit in my own delayed diagnosis because I had such a huge investment in being a well-person and told that story almost until the end – literally.

The bloody-mindedness that brought me so close to death or disability through denial and the creative re-configuration of the facts is now helping me to get better through a vigorous exercise routine. Characteristically, perhaps, I renounced the idea of joining an exercise group. What me? Doing step aerobics with a lot of flabby heart-attack victims in polyester tracksuits? You can’t be serious...!

Graham Mort, January 2008

Appendix two:

The nurse's story:

Haddon Residential Home Discharge Letter

Haddon Residential Home

Dear Matron,

Re: Miss Elsie MacFadyen

D.O.B. 01.06.1916

Next of Kin: Mrs Zachary (sister)

Mobility: able to walk with the aid of one carer or personal walking aid < 25metres

Hydration/ nutrition: able to feed herself but not always motivated to do so

Elimination: continent x 2. Able to self care once assisted to the bathroom, uses a commode at night.

Hygiene: can wash herself. Needs help x 1 carer for dressing and positioning in bed/ chair. Needs carers x2 and hoist to have a bath

Skin integrity: skin on sacral area and left heel is red but not broken. Small pressure sore to right elbow is healed.

Communication: hearing normal; sight – wears glasses to read; oriented to time and place and has no difficulty with understanding.

Medication: see enclosed sheet

Summary:

Miss MacFadyen has been treated in the ITU unit at Prince Edwards Hospital for the past 12 weeks following collapse with unstable angina and general debility. Prior to admission this frail lady of 74 years lived alone in the community supported by her elderly sister.

Although Miss MacFadyen's condition is now stable our risk assessment shows that her overall level of health and ability to self care are poor, falling below an acceptable stand for return to her former home. In addition, her sister has hypertension and is unable to renew the level of support offered before this period of illness.

Although Miss MacFadyen's mental faculties are satisfactory for her age her mood is low; she lacks insight into her current health status and her prognosis for the immediate future. As a consequence she holds on to an unrealistic desire to return to her former home.

Yours sincerely,

Sister

CCU

Prince Edwards Hospital

The patient's story:

Miss MacFadyen regrets

After three months in the ICU, you'd think that they'd want shot of me. I keep hoping that they'll need the bed for someone really sick and kick me out. So it was with some excitement that I watched a young man in a white coat hurry up to my bedside this morning. I should've known better. The young doctor wasn't interested in me and my health, but came to tell me about my poor ailing sister. I'm sure it has been hard for her. I know she doesn't like running the house on her own and she's always been frightened of the dark. You never really grow out of being the youngest, even in your eighties. But why her suddenly raised blood pressure should keep me in bed, I'm sure I don't know. What a waste!

'Your sister feels that she cannot cope with the extra work of your return home' the eager young doctor told me earnestly.

I didn't scream 'But it's my house! I pay the bills!' I smiled like I know an elderly lady should. He doesn't know how I long to be able to wake up and look at my own pretty curtains and eat breakfast with a view of my cherry tree. To him, I know, I am a patient to be processed according to the most appropriate protocol.

'Instead we're arranging for you to go into a rest home.' Clearly I'm meant to feel or even express some gratitude at the prospect of being dumped in a holding ground for pre-corpses. I don't nod. But I don't bark either.

The rest home exceeds my expectations; it is grimmer than I could have imagined. The food is appalling, the staff largely absent, the inmates mad, smelly and unpredictable. Now I'm off the critical list, I share my living quarters with others. Our doors are locked to prevent 'confused ladies' from leaving. Nothing confused about wanting to leave here. Lily searches for the jewellery she says the nurses have stolen, or she would, if only she could get out of her chair. Sadly Lily can still speak; she accuses the orderlies loudly, pointing a knobbly finger as they pass, inured by the repetition of her charges of theft. Agnes no longer speaks, but she whistles cheery tunes of the 1940s at barely audible levels. Her endless blitz spirit is no less wearing than Lily's outrage. Dennis winks whenever he catches my eye and shouts across the room 'Rum lot eh!', except when he's wet himself and pretends to be asleep. The only thing more disturbing than these characters is when they die. Their bodies are removed without explanation, only to be replaced with a new demented soul.

My sister visits to check up on my welfare. 'Must be lovely to be cared for!' she sighs.

The relative's story:

Mrs Zachary's Lament.

My sister, Elsie, had been in hospital well over two months. I'd been visiting her as often as I could - at least twice a week. I couldn't face going some days— I was so tired and worried. We nearly lost her at one time, when she was rigged up with all those tubes in intensive care. But then I would remember Elsie's laugh and all the good times we've had over the years and I kept on visiting.

I went in one week as usual and Sister and I got talking. She asked me what I thought about Elsie coming to stay with me when she got out of hospital. She asked me to think about it and let them know. I couldn't tell Elsie. I needed to think about it and I didn't want to give her false hope.

I got really anxious on the bus on the way home. I love Elsie and her company but the thought of her being at my house with her angina... the responsibility of it felt enormous. I'm on my own and have high blood pressure – it had been really bad the last few weeks – and what would happen if anything went wrong during the night? What would I do? What if I let her down? What if the worst happened?

I rang the GP to talk it through. In the end, he thought it would be best if Elsie went to Haddon, a nursing home.

“We don't want you both poorly, Mrs Zachary.”

I've only been to the home a couple of times. It takes me an hour and a half to get there, so I can't go as often. I feel awful about it. There's my big sister, Elsie – who is as bright as a button – and I know she is in the wrong place. I can't bear to think of it. I still feel responsible.

References

- Aldiss, B. (1999) *When the Feast is Finished. Reflections on terminal illness*. London: Little Brown.
- Burke, L. (2008) *The Country of My Disease: Genes and Genealogy in Alzheimer's life-writing*. *The Journal of Literary and Cultural Disability Studies* 2(1): 63-74.
- Davison, C Frankel, S and Davey-Smith, G. (1992) *The limits of lifestyle: reassessing 'fatalism' in the popular culture of illness prevention*. *Social Science and Medicine* 34(6) 675-685.
- Davison, C Davey-Smith, G and Frankel, S. (1991) *Lay epidemiology and the prevention paradox – the implication of coronary candidacy for health promotion*. *Sociology of Health and Illness* 13 (1): 1-19
- Demicheli, V, Jefferson T, Rivertti A and Price D (2005) 'Vaccines for measles, mmps and rubella in children', *The Cochrane Database of Systematic Reviews*, 4. (Art. No.: CD004407.)
- Elwyn, G and Gwyn, R. (1999) *Narrative based medicine Stories we hear and stories we tell: analysing talk in clinical practice (Education and debate)* *BMJ*; 318:186-188 (16 January)
- Frank, A. (1995) *The wounded storyteller: body, illness and ethics*. Chicago: Chicago University Press.
- Gillman, M Swain, J and Heyman, B. (1997) *Life History or 'Case' History: the objectification of people with learning difficulties through the tyranny of professional discourses in: Disability and Society, Volume 12, Issue 5 675 – 694*.
- Goodley, D (1996) *Tales of Hidden Lives: a critical examination of life history research with people who have learning difficulties in: Disability & society, Volume 11, Issue September 1996, pages 333 – 348*.
- Greene, R. (1971) *Sick Doctors*. London: Heinemann Medical.
- Greenhalgh, T and Hurwitz, B. (editors) (1998) *Narrative based medicine. Dialogue and discourse in clinical practice*. London: BMJ Books.
- Greenhalgh, T. (1998) *Narrative based medicine in an evidence based world*. In Greenhalgh, T and Hurwitz, B. (editors) *Narrative Based Medicine: Dialogue and Discourse in Clinical Practice*. London: BMJ Books.
- Hilton, S Petticrew, M Hunt K. (2007) *Parents' champions vs. vested interests: who do parents believe about MMR? A qualitative study*. *BMC Public Health*; 7:42. at: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1851707> accessed 03.06.09
- Hunter, KM. 1991 *Doctors' stories: the narrative structure of medical knowledge*. Princeton, NJ: Princeton University Press .
- Illich, I. (1976) *Limits to medicine: medical nemesis, the expropriation of health* London: Boyars.
- Kearney, R (2002) *On stories. (Series: Thinking in action)*. London: Routledge.

Moerman, D. (2002) *Meaning, medicine and the 'placebo effect'*. Cambridge studies in medical anthropology. Cambridge: Cambridge University Press.

Oakley, A. (1980) *Women confined: towards a sociology of childbirth*. Oxford: Martin Robertson.

Porter, R (1997) *The Greatest Benefit to Mankind: A medical history of humanity from antiquity to the present*. London: Harpercollins.

Prendergast, C (2008) The unexceptional schizophrenic: a post-postmodern introduction. *The Journal of Literary and Cultural Disability Studies* 2(1): 56-62.

Available at: <http://jlclds.lupjournals.org/default.aspx?content=0201prendergast> accessed on 03.06.09

Rose, S Bisson, J. Churchill R, Wessley, S (2002) Psychological debriefing for preventing Post Traumatic Stress Disorder. *Cochrane Database Systematic Review*: 2. (Art no CD000560). In Stein, D J Seedat, S Iversen, A and Wessley, S. (2007) *Post Traumatic Stress Disorder: medicine and politics*. *Lancet* 369, 139 -144

Sacks, O. (1986) *A Leg To Stand On*. London: Pan.

Salter, B. (2004) *The New Politics of Medicine*. Basingstoke: Palgrave Macmillan.

Scheper-Hughes, N. (2002) Coming to our senses. *Anthropology and genocide*. Page 348-381 In 'Annihilating Difference. The Anthropology of Genocide.' Edited by Alexander L. Hinton. University of California Press.

Sinclair, C (1998) *A Soap Opera from hell. Essays on the facts of life and the facts of death*. London: Fourth Estate.

Strong, P (1979) *The ceremonial order of the clinic: parents, doctors and medical bureaucracies*. London: Routledge, Kegan Paul.

Note on the authors' use of story

One of us uses reflection as a written medium with young children; stories captured close to an event have an immediacy of quality that is altered as time passes. Another struggles with the difficulties with truth and reality in students' written accounts of professional practice where assessment for academic credit biases the writing style and authenticity of the text. One of us has written orthodox, empirically-justified research papers and yet feels that the truest truth of her research was represented in the fiction that she writes.

[i] Paul Ricoeur in his three volumes of 'Temps et récit' (1984, 1985, 1988, published by Seuil Paris) or 'Time and Narrative' (1983, 1984, 1985, published by the University of Chicago Press) establishes a philosophy linking personal and narrative identity which is constrained, under constant evaluation and revision.