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5 Use of Patient Stories in Health and Social Care

JANET HARGREAVES, HANNAH BRADBY AND MARY ROBSON

Abstract

Recounting stories is a powerful medium through which humans frame and reframe their experience. Within health care patients are encouraged to tell their own stories and these have growing relevance in diagnosis and management. This paper uses one autobiographical account, written for the authors, to explore some of the issues this raises. It is argued that whilst stories have an important role to play, they may also be counterproductive to full understanding and management of health and illness.

Key Words

Story telling; health and social care; health and illness.

Introduction

The Department of Health report on arts and health (Cayton, 2007) has encouraged creative artists, health practitioners and academics engaged in delivery and education for health and social care to actively use and embed creativity into all aspects of their practice. This development is further supported by the NHS Next Stage Review, initiated in 2007 and led by Lord Darzi (2008) which encourages innovation, and a strong patient centred focus.

The Creativity in Health and Care Workshops programme (Brodzinski and Munt, 2008) was an Arts and Humanities Research Council funded seminar series. It involved a series of investigative workshops aimed at interrogating the subject of creativity with an over-arching objective of extending the understanding of the problems and possibilities of applying creativity within the health and care sector workforce. The workshops drew together an interdisciplinary panel of researchers and practitioners who were already addressing this subject in their work, in order to harness thinking from a range of perspectives and allow the rigour of academic research to interact with the

critical engagement of practitioners and policy makers. Outputs from this program are due for publication in a special edition of *Health Care Analysis* in autumn 2009.

One of the areas of creative practice that featured within the workshop series was the use of patient's narratives and stories in diagnosis and therapy. 'Story' and 'narrative' are both used as descriptors of personal accounts. In this paper we use the term story to describe the description that people may give of the history of a particular episode in their lives. Narrative has come to have a specific and technical meaning in some sociological analyses of accounts of illness and disease while story remains a more everyday term. While there is considerable overlap between the two words, we understand narrative to refer to a potentially more fragmentary account, whereas story tends to mean a more developed, finished telling of events, perhaps as a result of frequent re-tellings.

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.¹

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, as a form of evidence, as a method whereby evidence is evaluated and as part of the therapeutic process. The status of patients' stories as part of the evidence for diagnosis and decision-making about treatment and care plans has risen and fallen. Through exploration of this phenomenon the workshop participants explored their own and other's stories, wrote narratives and sought other stories that might develop this particular theme. By chance, the author Graham Mort was recovering from major illness at the time and agreed to write his autobiographical account, which forms the focal point of this paper.

¹ 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.

Nabokov and the Angiogram

A new chapter in health fiction: Graham Mort, January 2008

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. Following a dropped catch, 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. 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 the local hospital.

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 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'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, 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. 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.

An MRI scan was arranged to see whether or not a herniated spinal disc might be referring pain into my shoulder and chest.

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.’ 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. 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. On Saturday evening I experienced such painful symptoms that I went to A&E at the local hospital. 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 over-riding 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 could add 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...!

Problematizing Stories

A technologically and statistically sophisticated scientific medicine may have become less attentive 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).

In addition to its use as an aid to diagnosis, 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. However, Graham Mort's story suggests a number of ways in which narrative may not be an unconditional good:

- What if patients' stories are compelling but wrong?
- What if different stories offer a truth that is denied by another? How should the difference be resolved?
- What about the stories that cannot or should not be told?

What if Patients' Stories are Compelling but Wrong?

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. 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. Our reading of his story is that 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.² After the shock of an unexpected quadruple by-pass Graham Mort writes that he has not (yet) accepted the disjunction in his own story of himself as a well man.

Graham credits his stubborn maintenance of his own narrative with bringing him close to his own death. A contemporary parallel within the UK may be the 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. It may be argued that, faced with a difficult decision about one’s own children, parents chose to ‘fit’ their own narrative to the one that most aptly matches their personal view, such that not giving the vaccination may match to ‘caring parent’, whereas giving the vaccination equates with ‘rational, altruistic citizen’.

What if Different Stories Offer a Truth that is Denied by Another? How Should the Difference be Resolved?

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. In many health care situations the ‘patient’s’ story does not sit in isolation from that of others. The child may offer a different perspective from the parent, and the husband the wife. Well documented cases of remembered abuse, and of false memory syndrome Hyman et al. (1998), Kaplan and Manicavasagar (2001) illustrate the complexity of wishing to accept and respect the truth of a given story, whilst acknowledging that it may not be accepted by others and that it may cause hurt.

² Graham has explored this further observing ‘not exactly’ – he felt that literature had produced a solution that science hadn’t, and as a creative writer that was particularly satisfying. He adds that he also had that slightly smug feeling of having established his own narrative when the medical profession had given him no conclusive diagnosis. Essentially, their story was incomplete, so he completed it in his own way.

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.

What about the Stories that Cannot or Should not be Told?

If patient stories are to be 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 un-shaped or not fashioned into a satisfying expression of suffering potentially allows others to construct their own 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. Graham Mort is able to tell his own story, but in doing so shows that the way that others receive and interpret it can be harmful, by deflecting scrutiny away from his dangerous symptoms.

However, in debating his story with others the possibility that stories *should* not be told was raised. These stories may include the revelation of abuse and misery, which is told to a therapist but has a different meaning and use when related to a wider audience, for example shared through research, literature, art, news or documentary features.

This challenge to the legitimacy, the right even, of individuals to tell their own and others stories publically no matter how bleak, and the status of that story once it is in the public domain raises questions at least about ownership, respect and public interest. Recent examples within the UK might include the deaths of Jade Goody and Baby Peter. This paper makes no attempt to debate

this complex area but acknowledges that the question raised by considering that some stories should not be told is an increasingly important one.

The Place of Story Telling in Health 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).

Attending to patient perspectives has also 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. They also support the sort of organisational reform to introduce 'user perspectives' in commissioning and managing service provision espoused by Darzi (2008). Graham Mort's account of his own experience has illustrated the power of narrative, and enabled a critique which challenges some of the current orthodoxy.

Conclusion

In this paper we make no claims to definite answers, frameworks or plans, only questions and health warnings. We are concerned that a rush to reconfigure care as ‘patient centred’ will allow patient story telling to become the latest quick-fix dogma, ill defined and therefore primed to fail. Graham Mort offers a rich and insightful account of his illness but we are unsure whether there is a means whereby his and other patients’ stories, should or ought to be systematically incorporated into health care. 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.

Acknowledgement

Graham Mort writes poetry, radio drama and short fiction and is a senior lecturer in Creative Writing at Lancaster University. His autobiographical, reflective account of recent illness and recovery forms the central focus of this paper. The authors acknowledge with grateful thanks access to his ‘story’ which has influenced the development of our thinking, and subsequent critique.

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