Narratives in Healthcare

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Abstract

In this article, the narrative is defined and the elements of the narrative are elucidated. Three lenses through which one can view the role of narratives in healthcare are discussed. Firstly, organisational narratives help to foster social capital in the organisation, and therefore contribute to the people aspect of the knowledge management initiative in the organisation. Secondly, the recuperative and relationship building roles of illness narratives are described. Thirdly, narratives from the practice of narrative medicine are explored. The article concludes by proposing four requirements for narratives to be effective, namely, effective listening skills, the availability of time and place for storytelling, and the codification of narratives.

Introduction

Jean-Dominique Bauby was the editor-in-chief of the French Elle magazine. On 8 December 1995, he was struck with a massive stroke which damaged his brain stem, leaving him with the “locked-in syndrome”. He was paralysed from head to toe and could only communicate by blinking his left eye. With the help of a speech therapist, who introduced him to an alphabet in which the letters were ordered according to their frequencies in the French language, he dictated the book “The Diving-Bell and The Butterfly” to Claude Mandibel at Room 119 in the Naval Hospital at Berck-sur-Mer on the coast of the French Channel, where he was warded. In his book, Bauby described his initial hopes that he would very quickly recover his movement and speech. He filled his roving mind “with a thousand projects: a novel, travel, a play, marketing a fruit cocktail of his own invention”, projects which he would undertake once he had regained his ability to walk and speak. Alas, as time progressed, he realised that this was not to be. He wrote about the devastation and despair upon discovering that he was a quadriplegic and would have to be confined to the wheelchair for the rest of his life. He described the vacillation of his emotions over the sudden dependence on others for even the simplest of tasks, the amusement and pleasure one day of having someone bathe him and wipe his bottom, only to feel unbearable gloom and sadness the next day about the same thing. He painfully wrote about the sadness when he thought of the little pleasures in which he participated before the stroke. Bauby’s account about his experience of the “locked-in syndrome” in his book is an example of a narrative in the context of healthcare [1].

What exactly is a narrative? Several definitions that have been put forward are listed below:
A narrative is a spoken or written account of connected events [2]

A narrative is a verse or prose accounting of an event or sequence of events, real or invented. [3]

A narrative is a representation of past events in any medium: narratives can be oral, written, filmed or drawn. [4]

A few elements of narratives can be gleaned from the definitions. A narrative: (1) can be a spoken, written, filmed or drawn account; (2) can be in verse or prose; (3) can be used to represent real or fictional events. Greenhalgh and Hurwitz [5] added four more features to this list: (1) narratives have a beginning, several intervening events, and an ending; (2) narratives incorporate both the viewpoints of the narrator and the listener.; (3) narratives are concerned with individuals, how they feel, and how others feel about them; (4) narratives are absorbing and memorable, and they engage the listener and invite him to interpret the account, i.e. to “live through” them. Narratives are such an essential part of human nature that Fisher [6] has used the term *homo narrans* to label human beings. To need to narrate is part of the universal human trait of needing to be understood, and needing to be in communication even if only from the margins [7].

There are at least three lenses through which we can view narratives in the world of healthcare. Firstly, there are organisational stories. These are stories whose main purpose is to create and strengthen social capital, and in doing so, contribute to the success of the organisation’s knowledge management initiative [8]. Secondly, there are illness narratives. These are stories people tell about their subjective experience of illness. Illness narratives have become a major literary genre. They are a source of knowledge about the disruptive nature of illness and their therapeutic potential has been recognized [9]. It must be clarified at this point that “medical sociologists distinguish between disease (the diagnostic entity) and illness (the way that disease is perceived, enacted, responded to by a person, in relationships with others)” [10]. Thirdly, there are stories that are told by physicians that practise medicine with narrative competence [11]. Many authors use the term “narrative” interchangeably with the term “story”. In this article, I too, have adopted this stance. Indeed Frank [12] has noted that it is more natural to say “let me tell you a story” rather than “let me tell you a narrative”.

**Organisational Stories**

Stories build social capital because they are told with three possible objectives, i.e., to reaffirm, to create, or to redirect the relationship within which the story is told. In fact, the story itself, which is an act of telling, is the relationship. Stories are told with (and not just to) listeners. The listeners in a storytelling session are not incidental to the act of storytelling; they are a critical element of it as the stories that are told reaffirm what the participants of a storytelling session mean to each other and how they relate to each other. [12]

Cohen and Prusak [8] suggested several ways in which stories build and support social capital in the organisation: (1) stories convey the norms, values, attitudes, and behaviours that define social groups more fully than any other types of communication; (2) stories are memorable and contain lessons that can be applied directly to real life as they “show by example” (p. 112); (3) storytelling sessions are social events which help to connect people and define them as members of a social group; (4) stories recount past events and
bond people together; (5) stories help people to frame their thinking and allow them to bring reality into an abstract discussion.

In addition, they suggested a taxonomy of stories, stressing that the categories they propose are not watertight and that any one story can belong to one or more categories. *Organisational myths* are stories that define the organisational culture. These stories are fundamental to the organisation in the sense that they encode how the organisation views itself and its relationship with the world, describe the priorities of the organisation, and explain how things work and get accomplished around the organisation. These stories centre on the founders, or on critical events that the organisation has faced in the past. An example of an organisational myth that centers on the founder is the one that David Packard, one of the co-founders of the Hewlett-Packard Corporation, related in his book, *The HP Way* [13]. In the book, Packard related the story where he was walking around the shop floor with the manager of that unit. During his walk, he stopped to watch a machinist make a plastic mould die with great care and reached out to touch the carefully polished die with his finger. The machinist exclaimed, “Get your finger off my die!”, to which his manager replied, “Do you know who this is?” The machinist countered, “I don’t care.” Packard stressed that the machinist was not taken to task for this incident. Instead he was commended for being proud of his work. This story illustrates the fundamental aspects of the organisational culture at Hewlett-Packard: (1) a strong belief that each person in the organisation and the job he does is important; (2) individuals are to be treated with consideration and respect; (3) little details make the difference between an average and a great product. The stories Robert Watson tells in his book about the management philosophy at the Salvation Army repeatedly lay down the order of priority in the Army’s unique way of meeting human needs called “holistic ministry”, i.e., soup, then soap, then salvation [14].

*Hero stories* are stories that tell of successes and triumphs over great trials and difficulties, usually owing to the courage, persistence, determination and fortitude of one individual. These stories also tell of heroic gambles. Hero stories seek to inspire the listener. The story of Helen Keller is such a story [15]. It tells of Helen, who was born with the sense of hearing and of sight, catching a fever at nineteen months of age, and subsequently becoming an impossibly difficult deaf-blind child. It tells also of her courage in the face of adversity that allowed her to overcome the odds through perseverance and the help of a dedicated Irish-American teacher named Anne Sullivan. Despite the odds stacked against her, Helen managed to accomplish much in life, graduating from Radcliffe College cum laude, becoming a successful writer and an active fund raiser for the American Foundation for the Blind. The stoical attitude that she adopted made her a heroic role model for many. She has become a timeless icon and the single disabled person that Americans can name.

Many hero stories were told during the severe acute respiratory syndrome (SARS) outbreak in 2003. One such story had to do with Carlo Urbani, a 46-year old physician and infectious disease specialist working with the World Health Organization. Dr Urbani was an Italian physician who, at 22, left his hometown of Maiolati Spontini to work in Africa. In 1999, he accepted the Nobel Peace Prize on behalf of Médecins sans Frontières, an international humanitarian group dedicated to providing medical care to victims of political violence or natural disasters. In 2003, he was called to the Vietnam-French hospital in Hanoi as an epidemiological expert. It was in Hanoi that he alerted the world to SARS. Without his early warnings of the importance of infection control safeguards and the need for heightened global surveillance of SARS, the outbreak could have been far worse. He started treating Vietnam’s only index patient, a Chinese-American businessman who brought the disease into
By March 11 he realised he himself had been infected with the disease. He succumbed to SARS in Bangkok on March 29. As a memorial to Dr Urbani, colleagues from around the world have proposed naming the SARS virus after him. [16] This is a story of a fallen hero. Owing to the nature of healthcare, which has much to do with caring, curing, saving, helping, healing, and relieving, it is naturally replete with hero stories.

**Failure stories** caution the listener against certain acts as these offend the organisational culture. They define the out-of-bound markers in the organisation and therefore contain the dos and don’ts that one must know to function effectively in the organisation. Failure stories are therefore a part of one’s organisational navigation knowledge. **War stories** are stories of disasters. These stories have a connecting experience and they build social capital. These two story types were frequently recounted during the Singapore National Kidney Foundation (NKF) controversy when it was revealed that the NKF CEO earned in excess of half a million Singapore dollars a year and flew first class when he travelled at NKF’s expense. This flew in the face of the NKF’s culture of transparency, accountability and prudence. The war stories that followed shortly after were on the public outcry against NKF by cancelling their monthly donations, on the setting up of an online petition calling for the CEO’s resignation, and on the call for greater transparency by charitable organisations in general.

**Stories of the future** are stories that can unite organisational members towards a goal for which they can strive. These stories are used by charismatic leaders to draw people into a cooperative effort, gelling them into a community in the process. Such stories create a collaborative culture by drawing organisational members together and showing them what they can achieve if they work together. Several articles have been written predicting what the hospital of the future would be like. Some trends that can be expected are increased pressure to contain cost, increased integration and alliances among healthcare providers, increased use of information and telecommunication technologies, and increased adoption of breakthrough technologies [17]. The CEO of a hospital that explains these trends to his colleagues, paints a picture of his hospital 10 years on, and describes the steps he plans to take to achieve that vision during a speech he makes in an annual staff dinner, say, would be telling a story of the future.

### Illness Narratives

Illness narratives refer to the reflective and insightful autobiographical accounts of illness. They are not merely chronicles of events, but can provide valuable insights into how patienthood, brought upon by the assault of illness, is experienced as a disruption of selfhood. The very act of narration itself is an important way of making sense of the illness, of restoring personhood and connectedness and of reclaiming the illness experience. [9] When life is hard, such as the demoralisation that one experiences when one is afflicted with an illness, stories can also provide the narrators some distance from their illness. Stories have a recuperative role and can be used to recuperate persons, relationships, and communities. Stories have a relationship building role, and listening to a story outside of a relationship is meaningless. Those who tell stories are most concerned about being heard, wondering if they will find others who will answer their call for a relationship. [12] Illness narratives celebrate the subjectivity and uniqueness of the illness experience, which is often objectified and depersonalised by the healthcare system.
Illness narratives are typically organised in a chronological plot style, starting with the time before the illness, the onset of illness, the crisis point, and the resolution of the crisis. Therefore, the questioning technique used can follow a lineal sequence: past–present–future. [9]

General practices offer physician and patient the opportunity to exchange stories for over half a lifetime. The narratives allow general practitioners to form special relationships with three cohorts of patients, namely, those of the same gender and approximately the same age, those of approximately the same age as the physician’s parents, and those approximately the same age as the doctor’s children. Patients in the first group progress through life along with their physicians, and a common cultural context holds them together. Patients in the second group face the same problems with deteriorating health as the physician’s own parents, and their common struggle provides the context for the relationship. Patients in the third group grow up along with the physician’s own children, and their common passage through the most exciting and complex transitions of their lives binds physician and patient. The narratives shared over a prolonged time allow strong bonds to be formed, engendering trust and effective care. [18]

Illness narratives have also appeared on the World Wide Web. McLellan [19] wrote about the long series of postings on Gabe Catalfo’s experience with acute lymphocytic leukemia, written by his father, Phil Catalfo, on Whole Earth ‘Lectronic Link (WELL), a conferencing system that started in 1985. This is a unique work compared to traditional illness narratives like poems and short stories (e.g. Bauby’s “The Diving-Bell and The Butterfly”) because while traditional narrative forms are complete and finished, Phil postings about his son’s experience is an ongoing and unfinished account of Gabe’s experience. This account, which has been written as a chronicle of daily events, has enabled healthcare professionals to understand patients’ and their families’ experiences of illness better. Another major difference is its involvement of the readers. In electronic narratives, the readers are not the same as the silent and unseen buyers of a book. The readers become active participants in the telling by:

- being concerned in asking about how father and son are coping
- acting as learners, seeking clarification on what has been posted
- acting as a source of advice and information, e.g. the poster that told Catalfo about a health information service available to the public
- acting as a source of emotional support for the Catalfo family, sending messages of encouragement, cheer, and congratulations when the treatment went well
- acting as volunteer researchers

In addition to the day-to-day treatment and coping issues, the illness narratives posted provide insights into the meaning of the illness for the father as well as for the family, and encompass the total experience of the illness, not just the progression of the disease. Online illness narratives (OIN) have several unique features. Firstly, they are unfinished. In a sense they are always “work-in-progress”. OINs are collaboratively constructed by the voices of many discussants along the way. Thirdly, they are interactive in nature, and the readers are not silent but they become active participants in the telling of the story, and they exert their influence on the story in different ways. Therefore, the authorship of an OIN is unclear. Fourthly, they are told in real time with a limited time perspective. Lastly, there is a certain rawness and emotional power in the postings that allow the actual experience to be told closer than through any other genre. Participants of OINs benefit by gaining access to experts in
many areas, and because the narrative is multi-authored, they get to see many perspectives on any single issue, but the downside is the lack of a formal mechanism for review of the postings. [19]

**Narratives from the Practice of Narrative Medicine**

These narratives are a product of the practice of medicine enhanced with narrative competence. An important idea is that people who are experiencing illness require physicians that are not just medically competent, i.e. physicians that can understand their disease and prescribe the appropriate medication and treatment, but also (and perhaps more importantly) physicians that can accompany them through their illness, understand their plight, and empathise with them. Narratives are seen as the vehicle that will allow for authentic engagements. Charon [11] has identified four central narrative situations in which physicians play a part: physician and patient, physician and self, physician and colleagues, and physician and society. Physician-patient narratives are used to bridge physician and patient, allowing the physician to join his patient in illness. They are told in words, gestures, and silences. Besides being therapeutic in themselves, these narratives allow the physician to enter into the world of his patients. Groopman [20] stressed that this melding of minds is important so that a clinical compass can be built. The physician needs to probe not just the patient’s body but also his spirit, to consider not just the patient’s physical repair, but also his psychological and emotional repair. This requires open dialogue – this requires the magic of the narrative. Clinical decisions cannot be made algorithmically as each person experiences his illness differently, has very different risk profiles, and is willing to give up different things to continue living.

Physician-self narratives are the reflections and self-examination of contemplative physicians when they attempt to make sense of their own emotional response to patients. Reflection also allows physicians to better understand the patient’s story and enable them to better navigate the uncertainty and devastation of illness. Physician-society narratives allow physicians to have frank and honest conversations with society about the imperfections of the medical system, the limits of medical knowledge and the fragility of life. It can be said that Groopman [20] achieves both these narrative types in his book, *Second Opinions*. In the book, he reflects on the complexity of medical decision-making. At the same time, he has a conversation with society about reality in the world of medicine, a world many wish to be perfect but is far from being so – a world where even the best physicians sometimes give bad advice and make serious mistakes.

Physician-colleague narratives are knowledge sharing episodes in which a physician participates with his colleagues, who may be other physicians or nurses, social workers, etc. These narratives build social capital and collegiality, and allow physicians to celebrate their roles in the healthcare system. In addition, knowledge sharing prevents reinvention of the wheel, spreads best practices, provides opportunities for peer learning, and provides a ready sounding board to air new ideas. [11]

**The Critical Complements to Narratives**

Narratives alone, no matter how well told, are insufficient. At least four other requirements are necessary for narratives to be effective in healthcare. Effective listening skills, the availability of time and place, and the codification of narratives are all necessary to ensure that the narratives are heard and preserved.
As it is important to hear out those who tell stories of their illness, and to answer their call for a relationship, listening skills are of paramount importance. Physicians must learn how to listen to their patients to convert the patient’s story into a diagnosis and a treatment plan, and nurses must learn the art of history taking in a new way, in a way that privileges the patient’s voice and in a way that listens out for meaning rather than just facts. Nichols and Stevens [21] listed six bad listening habits uncovered by research at the University of Minnesota. They found these habits to be almost universal, and used as a rationalisation for not listening, even when the listener knows and admits he should be listening. Firstly, the habit of faking attention. Listeners who fake attention deceive themselves and frequently get caught. Secondly, the habit of “I-get-the-facts” listening. These listeners miss the point of listening, which is rarely “to get the facts” but rather “to understand the idea”, “to grasp the meaning and significance” or “to look with me rather than at me”. Thirdly, the habit of avoiding difficult listening. Listening perforce takes energy and requires mental exertion. In addition, listening to the experience of illness is difficult and draining.

Fourthly, the habit of prematurely dismissing a subject as uninteresting. Here, the listener equates “interesting” to “valuable”. What is required is a change of attitude to views of even the most ordinary person as one who has some ideas to offer and from whom I want to take for myself those ideas of his. Fifthly, the habit of criticising delivery and physical appearance. This habit causes the listener to focus on the physical aspects (i.e. the clothes, accessories, or hairstyle worn by the speaker) or the speech (i.e. the foreign accent or “twang”). Instead of listening intently to the content, the listener gets distracted by mentally criticising the physical appearance or delivery of the content, adopting an attitude that “a person who talks like that cannot have anything worth listening to. Lastly, the habit of yielding easily to distractions that compete with the person talking refers to a lack of willingness to proactively shut out the distractions that inevitably interrupt many narratives, e.g. by closing the door, moving closer to the person talking, or mentally shutting out the distractions when all other measures prove futile. These habits have a serious consequence. They cause the listener, and in the case of healthcare, the physician, to lose the opportunity to learn something from what is being said by the patient.

Fig. 1 Traditional Chinese Character for the Verb “Listen”

The etymology of the traditional style of the Chinese character to listen (Ting1) (Fig. 1) clearly conveys the essential elements of listening and depicts listening as a complex and involved task. The radicals “耳” (Er3, meaning ear) and “王” (Wang2, meaning emperor) on the left, remind the listener to listen to the speaker as if he were listening to the emperor. The importance of giving full concentration is depicted by the radicals “十” (Shi2,
meaning ten or full) and “目” (Mu4, meaning sight or eye). The elements of empathy and whole-heartedness are represented in the radicals “一心” (Yi1 Xin1, meaning with one heart). Some narratives, e.g. pain narratives, are more difficult to understand, and therefore will require more effort on the part of the listener. They are especially difficult to understand because of their lack of coherence and structure, and because they are typically poured out in a haphazard way. In order to understand the narrative, physicians not only need to listen to the exact words used and the order in which they were uttered, but also match these with the body language involved.

The importance of time and place is evident. As Heath [18] so clearly puts it, “Stories can only be told if people have time to talk and time to listen and to hear. The richer the narrative, the more time is needed.” The time element of narrative was also highlighted by Bayliss [22]. He stressed that both physicians and patients need time for narratives – the physician needs time to listen and the patients, to deliver. He bemoaned the current situation where physicians are required to see more patients in less time, stating that it is not in the best interest of either party to do this as it lessens the intellectual satisfaction of understanding narratives. A lack of time and opportunity has been frequently cited as being a barrier to knowledge sharing [23], which is most effectively achieved through “a convincing narrative delivered with elegance and passion” [24]. A frequent intrusion to narrative episodes is that created by technology. Telephones, facsimile machines, and portable digital assistants have invaded the workplace, disrupting many narrative episodes with patients. It may be useful (or even necessary) for healthcare organisations to consider providing “Zen gardens”, or places of peace. These are “islands of non-technology” where people can concentrate, think, read, write or have a conversation uninterrupted by technology. [25]

Nonaka and Konno [26] have stressed the importance of “ba” (which translates approximately to “place” in English) as a shared space for human interaction (and narration is a form of human interaction) where knowledge can be created and shared. A “ba” can be physical, virtual, or even mental. In healthcare, an example of “ba” is nursing presence, which is seen to play an important role in the process of healing. Nursing presence has to do with “mutual openness with the other, entering the world of the other to see the objective from his or her standpoint, and coexisting for some moments in time and space”, and is

“an intersubjective encounter between a nurse and a patient in which the nurse encounters the patient as a unique human being in a unique situation and chooses to spend her/himself on the patient’s behalf. The antecedents to presence are the nurses decision to immerse him/herself in the patient’s situation and the patients willingness to let the nurse into that lived experience.” [27]

One way in which the nurse can “enter the world of the patient” to “immerse himself in the patient’s situation” is through the use of narratives. The patient lets the nurse enter his lived experience through the use of narratives. Narratives allow nurses to establish a relationship with the patients and be sensitive to their needs, to treat the patient as a person and not as a case amenable to technological solutions.
Godkin [28] worked on six features necessary for attaining nursing presence identified by Doona [29], and proposed a model of nursing presence comprising three layers of six hierarchical levels (Fig. 2). In Godkin’s model, the lower levels support the higher ones, and therefore must be in existence before the higher ones. It will be argued that narratives are a critical aspect of each of the three layers. The first layer, bedside presence, requires physical presence, and in essence, conforms to Nonaka and Konno’s “physical ba”. At this layer, narratives are used to establish rapport through interaction with the patient. In the second layer, clinical presence, narratives are used to understand the patient’s perspective in order to go beyond the scientific data. The last layer, healing presence, uses narratives to achieve attunement with each other. Here, the ability to relate closely to another person, to empathise, will enable a person to know what will work and when to act for a patient. Healing presence conforms closely with Nonaka and Konno’s “mental ba”, i.e. a shared knowledge context [26].

Finally, narratives need to be captured as codification is the only way the experience of illness can be made permanent for all to learn. This is being done with the Database of Individual Patient Experience (DIPEx; http://www.dipex.org/), a site launched in July 2001 by Ann McPherson and Andrew Herxheimer after their own experiences of illness (breast cancer and knee replacement surgery, respectively). They decided to start this patient experience website (hypertension and prostate cancer were the first two topics) after failing to find others to talk to about their illnesses. Currently, DIPEx is aimed at patients, their caregivers, family and friends, and also functions as a teaching resource for health professionals. The website contains interviews with everyday people about their own experiences of serious illnesses, health problems or health-related matters. Their aim is to cover 100 main illnesses and conditions, as well as areas such as immunisation, rare diseases, skin conditions, infertility, and chronic illnesses. The limitation is that the database currently represents the experiences and views of people within the United Kingdom. A website with a similar charter, but on an international scale, is badly needed as the experience of illness is
likely to be influenced by culture. Perhaps the most appropriate organisation to champion this effort is the World Health Organization (WHO).

Conclusions

In a healthcare paradigm where there is an increasing call for a more effective use of the organisation’s knowledge assets to enhance patient safety, avoid waste, reduce wait, and increase quality care [30], and for a more patient-centred approach, narratives can provide a way forward. In this article, three types of narratives, namely organisational myths, illness narratives, and narratives from narrative medicine, have been identified. The role that these narratives play in healthcare has been described. Lastly, four requirements before narratives can be truly effective in a healthcare organisation have been identified.

References

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