

Listening to patients' stories is important, but the challenge for health professionals is to find ways of using these narratives to improve practice and the patient experience

PATIENT NARRATIVES: PART 1 OF 7

Using patient stories to reflect on care

In this article...

- › Why listening to patient narratives is important
- › How patient narratives link to evidence-based practice
- › Impact of nurses' actions on patients' experience of care

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Abstract Buckley A et al (2016) Patient narratives 1: Using patient stories to reflect on care. *Nursing Times*; 112: 10, 22-25. There is an increasing emphasis on, and commitment to, using patient narratives in nursing practice and nurse education. Listening to the voices of those receiving our care is just the beginning. The challenge is to use these narratives to improve practice and the patient experience.

This seven-part series will present narratives from three fields of nursing: adult, mental health and learning disability. Each article will include opportunities to reflect on the stories presented and consider their implications for practice. Part 1 explores how patient narratives can be used as an evidence base for nursing practice. It uses a patient story to explore the unintended consequences of communication between a nurse and a patient, as well as how the environment in which patients find themselves can relay important messages.

Healthcare delivery has typically focused on patients' presentation of signs and symptoms, with management plans directed at their resolution and medical treatment. But if care is to be truly patient centred, health professionals have to acknowledge that patient stories – the illness narrative – that arise from their personal encounters with health and social care, should be the dominant voice.

The Francis Report (Francis, 2013) acknowledged a lack of collective responsibility in care provision and recommended that, as part of annual revalidation, nurses should be able to demonstrate: "commitment, compassion and caring for patients, evidenced by feedback from patients and families on the care provided by the nurse". In a response to Francis, the King's Fund (2013) acknowledged the influence of the patient voice and recommended that: "NHS leaders should encourage and nurture patient leaders to help build collaborative relationships and develop genuine co-production as a way of improving services".

In its revised Code, the Nursing and Midwifery Council (2015a) strengthened the importance of collaboration. It requires nurses and midwives to "listen to people and respond to their preferences and concerns" and "work in partnership with people to make sure you deliver care effectively". There is clearly a requirement for all health professionals to consider how an analysis of patients' experience of healthcare can, and should, inform service improvement and development.

While recent national inquiries such as Kirkup (2015) and Francis (2013) have revealed disturbing examples of poor-quality care, their recommendations highlighted the importance of giving a voice to the concerns and experiences of patients and their families. It could be argued that health professionals can only truly embody their professional responsibilities if they listen reflectively to patient stories and consider their position within the

5 key points

1 Patients' narratives can make a significant contribution to patient-centred care

2 Narratives invite an emotional response and offer a version of events that is different to those of professionals

3 Narratives should inform service improvement and development

4 Communication between nurses and patients can have unintended consequences

5 The environment patients are in can relay important messages to them that staff may not have considered

patient–nurse relationship. Indeed, nurse revalidation (NMC, 2015b) will require nurses and midwives to use feedback from service users to assess their compliance with the Code.

Nurses need to listen to, and value, the patient story if they are to refocus their priorities and truly position patients at the centre of care. This is not a new idea; indeed, Snowden (1999) suggested that the use of patient narratives can change listeners' understanding of their experience, and offer incentives for practice development and change.

Patients' experience of disease

There is an increasing commitment, particularly among social scientists, to move healthcare provision away from a focus on diagnostics, which define illness simply by disease presentation (Bury, 2001; Hydén, 1997). Instead, health professionals are encouraged to understand that individuals' experience of disease – their autobiography – can be influenced by social, cultural and, at times, political issues. For example, long-term conditions can be seen as an example of how disease affects patients' life trajectory. As their illness develops, they are compelled to move to a different path, walk along a different life-map and renavigate as they respond and adapt to a changing health status.

Frank (1995) suggested patients' lives becomes reconstructed in the context of illness, and that "telling stories of illness is the attempt, instigated by the body's disease, to give voice to an experience that medicine cannot describe". Kleinman (1988) acknowledged the value of the story contained in the illness narrative because it inherently "gives coherence to the distinctive and long-term course of suffering".

This seven-part series will present "illness narratives" from different fields of practice – words spoken by patients, clients and those "expert" in their care. We encourage you to engage with these stories and understand what is really being said by those who receive our services. We hope these narratives will encourage a more reflective and reflexive analysis of how health professionals' actions and responses to patients are perceived and experienced. These reflections should then inform your future professional practice and can be used as part of your revalidation activities.

Evidence-based practice

Nursing has become increasingly focused on evidence-based practice (EBP) in recent decades. Within the orthodoxy of EBP is a

BOX 1. THE PATIENT EXPERIENCE

James Hyatt's account from his time in hospital

"Four years ago I was diagnosed with cancer in my neck. The doctors removed it and said that it had come from somewhere else in my body. They gave me more tests but were unable to find any other cancer, so they discharged me. However, recently I went back to my doctor because I had become increasingly tired, had no appetite (even over Christmas!) and started to lose weight. My bones ached and my wife told me that my voice sounded different. I felt very poorly and had no energy at all. I was admitted to hospital where I had a range of horrible tests. The bad news was that they found cancer in my lungs and elsewhere.

"They did tell me I had cancer but said nothing about the future. I never thought to ask as I just assumed I was there for treatment. In fact, I made the assumption that my cancer was possibly treatable and talked very positively to my family and friends about my condition and recovery. I was looking forward to getting back home with my family.

"Two days later, I was transferred to the oncology ward, which only reaffirmed my belief that the diagnosis was right but that treatment would start. I was introduced to the other men within the bay, whose illnesses were very much like mine. We shared our stories. I appeared (rather naively) somewhat reassured that, like theirs, my treatment would soon start.

"The following day a nurse came to my bedside and explained, rather abruptly, that there was a 'very poorly patient who needs a bed' and told me I would be transferred yet again to another medical ward within the hospital, which 'deals with patients who have breathing problems'.

"My frustration increasing about yet another bed move (this was the fourth in a few days), I challenged the nurse, saying: 'But, I'm poorly, aren't I? And surely I need to be here so my cancer can be treated.'" The nurse was startled by my response. She clearly thought differently and must have known that any cancer treatment was pointless.

"The following day, after transfer to the respiratory ward, a nurse who I had not met before approached my bedside. I immediately noticed that she was wearing a badge on her uniform displaying her name, role and 'End-of-life care team'. Was she here to care for me at my end of life? No one had told me I was at the end of my life! I discovered very quickly that there would be no further treatment and that my condition was not curable.

"I told my family that my journey through the healthcare system felt like a 'jigsaw puzzle'. My experiences were isolated pieces of the jigsaw, but I was left to put the pieces together. It seemed like I accidentally found the pieces that told me I was incurable and nearing the end of my life. The pieces of the jigsaw eventually fitted together and a distressing picture emerged.

"At no time during my hospital stay did staff sit down with me to explain the results of my tests. Rather, I came to understand my illness not by what was said, but by what was done. The bed moves, the lack of treatment on the oncology ward, the staff who came to my bedside with name badges and those who I felt deliberately avoided me."

'Patient's name has been changed

"My experiences were isolated pieces of the jigsaw but I was left to put the pieces together. It seemed like I accidentally found the pieces that told me I was incurable and nearing the end of my life"

second orthodoxy for quantitative research. Webb (2001) argued that the preference for this type of research derived mainly from medical science as it is based in the scientific/positivist paradigm. The "gold standard" of research, and therefore evidence, is the randomised controlled trial (Parahoo, 2014).

The focus on EBP could be perceived to create a conflict between the typical professional nurse narrative and the use of

subjective stories. We might therefore ask what sort of knowledge and "evidence" these stories offer. Tevendale and Armstrong (2015) described some of the benefits of using patient narratives, including:

- » Increasing health professionals' understanding of issues affecting patients;
- » Reframing and refocusing the learner's understanding of the priorities of care for patients and their families;



Listening to patients' stories could improve practice and patient experience

» Closing the gap between human experience and theory.

We believe that, in addressing these crucial issues, patient stories do fit with the principles of EBP, as they offer the potential for reflectivity and reflexivity in action at a deep and nuanced level. Stories invite an emotional response and offer a narrative that is likely to differ from the narrative with which health professionals are engaged.

It can be argued that these two perspectives offer two distinct but complementary forms of knowledge that can be summarised as WHAT we do and HOW we do it. What we do is usually seen as being informed by the scientific evidence base; how we do it is informed by the sort of knowledge that comes from reflection on narrative. This series focuses on the latter; there will be little engagement with the wider evidence base, although this first article does explore the evidence underpinning narrative and its use in nursing.

Reflection on narrative: examples

We believe that the key to working with narrative is to be mindful of one's immediate response. Certain elements will strike us in the same way that a critical incident in practice might.

Below are examples of our own reflections on narratives from our patients.

Learning disabilities

Steve Mee describes his experience of listening to a patient narrative:

"I was supporting a man with a learning disability to tell stories about his life in an institution. He described the abuse he saw

meted out to people with a greater degree of learning disability than himself. "He said: 'They used to hit 'em...' [demonstrates a punch] 'They used to drag 'em.' [demonstrates an aggressive pulling action]."

"I had heard about the hitting many times, but the idea of being dragged like this was new. I was haunted by this image and reflected on the nature of powerlessness this indicated so graphically. If one is being hit it is possible to hit back and gain the upper hand. However, being dragged is being totally overwhelmed and taken somewhere you do not want to go. I went on to reflect on the nature of power and the experience of being overpowered.

"Nurses today do not literally drag people, but we might use forms of language that lead to compliance rather than concordance – patients feeling obliged to 'obey' rather than empowered to take part in the decision-making process. We might withhold something until we get our way. The theme of feeling powerless will apply just the same. And we might do all this while kidding ourselves we are working in a patient-centred way. What can we do to ensure that our patients do not feel overpowered? These reflections contributed to my book, Valuing People with a Learning Disability (Mee, 2012)".

Stroke care

Alison Buckley describes what she learnt from listening to a patient's story:

"Ivy Carter had previously been admitted to a regional neurosurgical unit following a spontaneous intracerebral haemorrhage. During her hospital stay she presented with disturbances in consciousness, acute confusion, florid hallucinations and delusions.

"After a protracted period of rehabilitation, Ms Carter recovered and was able to give a retrospective account of her hospital experiences. She remembered vividly a television being put in front of her, but she thought the events on TV were actually happening and that she was part of it. This was particularly frightening when violence or noise were depicted. Because staff had switched the TV on, she thought they were also part of the cause of the violence and reported feeling paranoid about the nurses' motivations. I reflected on this seemingly benign act and considered how good intentions can be misinterpreted by patients who are not in 'our reality'.

"Unless we listen to these accounts, we can never appreciate how our actions might be perceived and whether harm and distress is unknowingly caused. Although her

perception of reality was clearly distorted by her cerebral injury, Ms Carter's story is a reminder that unless we take time to understand patients' lived experiences, and perhaps attempt to view our actions and the environment through a 'confusion lens', we will never deliver the high-quality care patients have a right to expect.

"The hospital environment for the orientated patient may, at times, be confusing and hectic but for the confused patient it must be a profoundly disturbing and distressing place to be. As a result of my work with Ms Carter, I have started to research patients' memories of acute confusion as part of my PhD study."

Mental health

Louise Corless has been working with someone who wished to share their experiences of mental health services with third-year student nurses.

"The service user described her experience of asking for help. She stated: 'One of the most difficult things to do when I am in hospital is to knock on the office door to ask for help. When I'm feeling vulnerable and I need some support from a nurse, and the only option for me is to knock on the office door, it fills me with dread'.

"After listening to this narrative I reflected on my own practice before I entered higher education. Computers are in the office and nurses need to input information to ensure clinical notes are up to date. When someone knocks on a door our immediate response is to look to see who it is, but our actions at that point can have a significant influence on someone's feelings and perceptions about their own self-worth. What struck me most about the statement was what 'the door' symbolised: a barrier between nurses and patients intimating a potential power imbalance. I have now incorporated narratives into two modules with mental health students. My current research relates to how hearing these stories in a classroom impacts on a student's professional practice."

Reflective patient narrative

The first of the seven narratives in this series (Box 1) is based on the account of James Hyatt, who had been diagnosed with metastatic cervical lymph node enlargement four years before his admission to hospital. Although the histology revealed squamous cell carcinoma, despite extensive investigations, referral to a regional oncology unit and regular reviews, the primary source of the malignancy had never been found.

Mr Hyatt had presented to his GP with a short history of fatigue, unexplained weight loss, bone pain and a hoarse voice, which prompted urgent referral to the local hospital. He was admitted to an acute medical unit and had a range of diagnostic tests, which confirmed a primary lesion in his right bronchus and widespread metastatic disease.

Read Mr Hyatt's story and reflect on his experiences of being admitted to hospital following an unexpected change in his life trajectory. Think about his journey through the healthcare system and how details of his diagnosis and prognosis emerged, at times by chance, then consider the exercises in Box 2.

Box 3 gives further examples of how actions can speak louder than words in nursing practice.

What does Mr Hyatt's story tell us?

Mr Hyatt's personal account raises a number of issues, not least about the importance of timely information giving and the need to ascertain patients' understanding of their situation. Fundamentally, the nature of the ward to which a patient is admitted and the apparent benign interpretations of a bed move, along with the responses and behaviours of nurses, may reveal a great deal about diagnosis and prognosis. How often do we consider how decisions about a bed move, our name badge and the unit to which a patient is admitted "speak far louder than words"?

Clearly in Mr Hyatt's case there were missed opportunities to assess his understanding of his condition, and staff failed to be open and honest with him. It could be argued that the diagnosis took a little

BOX 2. POINTS FOR REFLECTION

- In Mr Hyatt's narrative, the nurse appeared surprised and uncomfortable when he challenged yet another bed move. Her expression gave away the reality of Mr Hyatt's prognosis, which had clearly not been communicated to him.

Think of examples when your actions and behaviours might have communicated an implicit message

- No one had explicitly told Mr Hyatt of his prognosis. He thought he was admitted for treatment but, in fact, his cancer was untreatable. It is possible that staff caring for him might have assumed that this message had been previously communicated, but do we avoid these conversations because we find imparting bad news difficult?

Have you ever found it difficult to give a clear message to a patient? If so, why?

- Mr Hyatt was transferred to the oncology unit and assumed that he was there for active treatment. He only realised his poor prognosis when he saw the nurse's name badge also stated "End-of-life care team".

What unconscious learning takes place for the patient in your working environment?

- Mr Hyatt's frequent bed moves initially led him to make some wrong assumptions before he realised what was really happening.

Is there anything in your service layout or routines that may convey a message to the patient?

while to be confirmed; indeed, he had presented to his GP as an urgent referral but numerous opportunities offered themselves throughout his stay for honest and sensitive communication.

Conclusion

As educators, it has been a privilege for us to work with patients and listen to their stories. All the stories we present are taken from true direct narrative. We have all found that these stories resonate strongly with our experiences in professional practice and have caused us to deeply reflect on our actions. Listening to patients' voices and their authentic experiences has become central to our endeavours. **NT**

Part 2 explores themes associated with the concept of consent and capacity

BOX 3. EXAMPLES OF ACTIONS SPEAKING VOLUMES

- Following surgery, a man was nursed on a nightingale ward. He was aware of "common knowledge" among patients that having your bed moved farther away from the nursing station meant you were getting better. He became worried when his move appeared delayed.
- A man with a learning disability was terrified of receiving a visit from any health or social care professional, as he was afraid they would remove him from his home, which had happened to him when he was young. In fact, the reason for their visit was to monitor his diabetes.
- A woman was prescribed antipsychotic medication while an

inpatient. After she was discharged, one of her friends, who was a social worker, said: "You know what that is for, don't you? They give it to people with schizophrenia." The woman stopped taking the medication as this had not been discussed with her and she did not believe it was her diagnosis.

- A person with a learning disability who was moving from a long-stay institution to a community home believed she was being sent to what she perceived as the "punishment ward". The reason for this perception was because the nurse supporting her in this move had previously been the ward sister on that ward.

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ARTICLES IN THE SERIES

- **Part 2** Consent and capacity: 16 March
- **Part 3** Power or empower: 23 March
- **Part 4** Communication: 6 April
- **Part 5** Empathy: 13 April
- **Part 6** Professional boundaries: 20 April
- **Part 7** Changing practice: 27 April