How narratives can change nursing practice

The students’ story
In our second year we attended a series of half-day lectures facilitated by expert patients, who shared experiences of often distressing and upsetting care. The expert featured narratives from nurses, while this final one presents the story of two student nurses on the learning disability programme at the University of Cumbria. It shows how narratives can be used to influence decision makers to improve services.

The students became involved with the national Changing Places campaign through their work as student quality ambassadors (SQA), a Health Education North West initiative to improve quality in practice (Box 1). Changing Places (www.changing-places.org) is a campaigning organisation for people who cannot use standard toilets and require extra space, a hoist or an adult changing bed.

The students identified a lack of accessible toilet provision within their local acute trust, University Hospitals of Morecambe Bay Foundation Trust, and became advocates for people with physical impairments and their relatives. We have chosen to end the series with this story to show how narratives can inform and influence a change in practice.

The students became aware of the power of stories during their training; they sought out and engaged with people from the local area, and the Changing Places campaign group, to hear their stories. The stories, below, were then presented to the management group of the local trust, prompting a remarkable result.

5 key points
1. Do you encourage patients to talk about their experience of care?
2. What should you do if a patient tells you about a poor experience?
3. Do you experience barriers in your organisation if you try to escalate a problem?
4. Could you use patient stories to illustrate the need for change?
5. What skills do you need to challenge practice?
appointments or inpatient stays. The specialist equipment available at the patient’s home was not always available in the hospital and we were horrified to hear that it was nearly impossible for this man to use the toilet when he was at the hospital.

At this time we had just been accepted as SQAs and were empowered to be involved with a charity; this was when we first heard about Changing Places.

Using the SQA ethos, we decided to talk to people about access to toilet facilities, primarily when visiting hospital for appointments or inpatient stays. We wanted to find out whether a Changing Places facility would be useful and make a difference to the quality of care patients received in hospital. In order to achieve this, we sought experiences in a number of ways:

- Listening to the parents of children with physical and learning disabilities at local specialist schools, Lancaster Down Syndrome Group and Lancaster Family Fun Day (specifically for people with learning disabilities and their families and carers);
- Talking and listening to adults with LD, and parents and carers in two self-advocacy groups;
- Attending a community meeting for people with profound intellectual and multiple disability.

We attended eight events and meetings, and listened to the issues faced by carers, including carers for people who have physical and learning disabilities.

We heard how difficult it is to manage without access to a bathroom with specialist equipment. James Carter described his daughter Amy’s experience of the local hospital as follows:

“One visit to outpatients was particularly traumatic. Our appointment was at 2pm, so we arrived around 30 minutes before, and it seemed very busy, so it was no surprise to learn that they were running late. Amy looked more agitated than usual and was getting quite upset, as she was trying to pass a bowel movement, which was difficult for her.

“The situation got worse, as the smell was embarrassing for her and she obviously did not want to sit in a soiled pad. We decided to take her to the changing room, which was just a standard disabled toilet.

“When Amy has a bowel movement and we are away from home, more often than not, we take her to a disabled toilet and lift her up from underneath her arms and my wife removes her pad, cleans her up and then puts a new pad on her. On this occasion she was far more emotional than usual because of the environment, and as we tried to change her, she began to scream very loudly. The more we tried to calm Amy down, the more upset she got.

“Then we eventually got her changed, we were all so upset that we made our apologies to the nurse and left without keeping the appointment. The situation would have been so much more dignified for her if there had been a changing room available.”

There have been many reports highlighting the health inequalities of people with learning disabilities and the importance of access to good healthcare. For example, Heslop et al (2013) stated that a “lack of reasonable adjustments to help people access non-emergency secondary care, particularly attendance at clinic appointments and for clinical investigations, was especially problematic”. Reasonable adjustments are a requirement of the Equality Act (2010), and by talking and listening to people’s stories it became apparent that a Changing Places facility was needed in our local hospital to allow disabled adults to be changed safely and in dignity (Giraud-Saunders, 2009).

Talking action

Our next step was to secure a place at the Equality of Access to Healthcare group meeting at the acute trust. This group reviews and improves access to healthcare for people with a protected characteristic, such as disability and age defined by the Equality Act, and is chaired by a deputy chief nurse. Many of the groups we had facilitated, or been invited to attend, had recommended this meeting as the place to present our findings. We realised that Changing Places facilities could have a really positive impact on access to healthcare for people with physical and learning disabilities, and we wanted the trust to listen to the stories and to act on them.

At the meeting, one of us presented the practicalities and the challenges faced by the people we had met. The other delivered the stories in the people’s own words. We brought the voices of patients we had spoken to into the room and they were listened to. The stories are presented in Box 2.

We finished with a request for Changing Places facilities within the trust with a quote from a patient who had said: “Please make a difference to the lives of the people who need it the most.” This was followed by silence and, we like to think, a collective
Nursing Practice

Discussion

listening. While we took a breath and calmed our nerves we were aware that the others in the room were paying attention to our voices and the patients’ voices. Questions followed, information was shared and contact details were exchanged. We came away full of hope and promise.

A few weeks later we received the news we had hoped for from the deputy chief nurse, and lead for inclusion and diversity at the hospital. She had discussed the Changing Places facility with the director of estates for the trust and they had agreed to add this to the estates strategy for implementation over the next five years. See Box 3 for her feedback on our presentation.

Reflection on our experience

As students, we learn about leadership, we are taught about good and bad practice and we want to be advocates for change for our patients. But how easy is it to take responsibility for the stories we hear?

We wanted to stand up and say “listen to what these people are saying”. While this was a huge challenge, we took it on because we had cried over these stories and, more importantly, we felt disempowered on behalf of everyone who shared their stories with us. We shared their frustration.

We are only just starting our nursing journey: we are not yet qualified, and have our final year to go, but we feel we have found one of the best items in our toolbox as we head to a future as learning disability nurses. We have learnt that if we listen, if we pay attention and act, then change can happen.

BOX 3. FEEDBACK

Student learning disability nurses Holly and her colleague, Heather, shared their work with the trust’s Equality of Access to Health group. Their presentation was confident and moving. They provided us with clear evidence that the experience of patients with learning disabilities, families and carers who needed to access our services, was not always as it should be. The patient and carer stories were very humbling and raised an awareness that something needed to be done. Holly and Heather have highlighted in this article that it is important to listen, but then what? How could I help?

The trust is currently developing a 10-year estate plan, which forms part of our “Better Care Together” strategy to ensure patients get the right care, at the right time and are cared for in an appropriate environment. As a result of the evidence provided at the meeting, I have been able to have meaningful discussions with the estates and facilities lead, and it has been agreed that improved changing and toilet facilities for patients with learning and physical disabilities, their families and carers will be included in the plans for each of the main sites.

Lynne Wyre is deputy chief nurse and lead for inclusion and diversity at University Hospitals of Morecambe Bay Foundation Trust

Reflection points

Previous articles in the series have posed a number of reflective questions for readers to consider. This week there are just two:

» Student learning disability nurse Holly and Heather listened to the stories and were advocates for the people that they met. Have people told you stories? What have you done to address the issue at both an individual and organisational level?

» Have you ever heard a story and wanted to make a change? What has been a barrier to making a change? If you have been successful, what was it that enabled the change to come about?

Conclusion

Our vision with this series was to present an array of stories that highlighted different themes that are applicable to all fields of nursing. We wanted you to recognise the power of stories and hoped that the themes emerging from the narrative would resonate with you on a personal and professional level.

We have demonstrated how narratives are an important source of evidence in their own right and can complement the “hard science” that informs our practice. We recognise that some of the accounts are extremely emotive and could make for uncomfortable reading. However, we believe that sometimes we have to be challenged in order to become motivated enough to act.

We feel this final article is an illustration of how stories can create such a response and lead to substantive change for people who access healthcare.

* The patient and her father’s names have been changed

References


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Students wanted to see whether the Changing Places facility would improve care quality