

Patient Voices: hearing the stories at the heart of healthcare

Abstract submitted as a theme paper for the Nurse Education Tomorrow 2006 conference under the theme:

The Role of the User

'Users and their carers should have choice, voice and control over what happens to them at each step in their care.'

NHS Cancer Plan (2000)

In *The NHS Plan* the Department of Health (2001) avowed its intention to place patients firmly at the heart of healthcare, envisaging 'a model of partnership where the voice of the patient is heard at every level of the service, acting as a powerful lever for change and improvement.'

The ensuing proliferation of policies, strategies, White Papers, initiatives and improvement plans, not to mention numerous patient surveys, consultation exercises and other attempts to involve patients in decision-making, have all espoused the intention of involving patients but how many of these laudable activities offer health service users an opportunity to 'tell it like it is'?

Patient stories have been recognised as making a significant contribution to understanding the patient experience (Greenhalgh and others); they acknowledge the patient's own areas of expertise, i.e. his or her own life and unique experience of illness. Further, research carried out by MORI on public perceptions of healthcare (Page, 2004) reveals that patients care more about being treated with dignity and respect than they do about mortality rates.

However, interviews and surveys may shape patients' responses by the questions they are asked and the actual, felt experience of patients and carers can be lost in the resulting mass of data. How can we – and the patients and carers we serve – make sense of the sometimes-bewildering experiences and often-overwhelming amounts of information that characterise modern healthcare?

Stories help us to make sense of our own experiences and those of others. This 'sense-making' (Weick, 1979) also helps to inform policy decisions to be made about how healthcare is conceived and to shape the systems that deliver it.

If we are to have truly patient-centred care, the voices of patients and carers must be clearly heard, and not only presented as what Yann Martel (2002) refers to as the 'dry, yeastless factuality' characteristic of statistics and reports.

There are many voices at all levels and in all sectors of the health service; without effective communication channels, many of these voices are still waiting patiently to be heard. To paraphrase Dylan Thomas (1951), we will not let them quietly into the night.

The Patient Voices programme offers an opportunity for those voices to be heard by all those who influence and all who are affected by healthcare policy and implementation. The programme aims to capture some of the unwritten and unspoken stories of ordinary people so that those who devise and implement strategy, as well as clinicians directly involved in care, may carry out their duties in a more informed and compassionate manner.

Patient Voices are 'digital stories' that combine the ancient art of storytelling with modern technology to convey the stories of patients, carers and health professionals in a unique way. Combining still images, small amounts of video, music and, usually but not always, voice, into a multi-media story of not more than three minutes in length, these short videos enable people who may never have found their voice before to tell and present their stories in an engaging and accessible medium that is available to a world-wide audience. Further, empowering patients and service users to tell their stories in this way is a way of encouraging them to acknowledge and take more responsibility for their own part in their care, a theme upon which Muir Gray (2002) elaborates in his notion of 'the resourceful patient'.

In addition to offering individuals a powerful medium through which to convey their personal experiences, digital stories are a means of facilitating reflection and helping people to make appropriate changes or improvements to their practice (Schön, 1983). Indeed, Schön's description of reflection in action might

have been written to describe the process of digital storytelling, which, to paraphrase Boud et al (1985) requires the storyteller to:

- re-capture an experience
- connect with the feelings associated with the experience
- integrate or assimilate what has been learned.

Digital stories invite viewers to echo this process of reflection, by relating to and trying to make sense of another's experience, often resulting in profound insights. And so a dialogue begins: dialogue that is so crucial in shaping our understanding of our place in the world and the way we engage with others (Freire, 1972).

These digital stories of healthcare offer an ideal tool for healthcare education for both pre- and post-registration nurses – and beyond. Initially used in elearning materials delivered by the UKHEP, they have also been incorporated in the RCN's Learning Zone materials and have been internationally acknowledged by quality improvement leaders as an ideal opportunity for bringing the voices of service users into healthcare education.

The growing collection of Patient Voices stories are increasingly finding their way into schools of healthcare around the UK, as a compelling means of stimulating reflection and discussion, particularly across professional boundaries.

Digital storytelling is one way of building communities of learning and practice (Lave and Wenger, 1991) weaving together the experiences of individuals into a tapestry that represents –and makes sense of - the collective stories of the community. Small enough to be easily disseminated across digital networks, and simple enough for most people to be able to create them, the stories are a democratic medium that can reach an international audience.

As we continue to work with patients, service users and healthcare professionals, we are increasingly forced to agree with Joe Lambert (2000), Founder and Director of The Centre for Digital Storytelling, who has this to say:

'I believe the notion of story, transformative reflection, and the capacities of computing machine being forged together into some sort of new life management process is catching on with people.'

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