The crisis of my life
digital storytelling as a radical response to crises in health and care
Pip Hardy

Pilgrim Projects/Patient Voices National and Kapodistrian University of Athens, 10th May 2014

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'The crisis of my life'

'To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity... I just wish he would... give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.'  
Anatole Broyard, 1992

Facing dragons

'No matter what form the dragon may take, it is of this mysterious passage past him, or into his jaws, that stories of any depth will always be concerned to tell...'
Flannery O'Connor 1969

Overcoming dragons

'People reach greater maturity as they find the freedom to be themselves and to claim, accept and love their own personal story, with all its brokenness and its beauty.'  
Jean Vanier 2004

Healthcare in crisis

• More people than ever before
• People living longer (in developed countries)
• More complex chronic disease
• Increasing mental illness
• Looming spectre of dementia
• People still dying from preventable deaths (in developing countries)
• Pressure to 'do more with less'
**A challenge**

‘Challenging dominant narratives and the status quo may be achieved through new genres (e.g. DS) and different people telling stories.’

Ochs and Capps, 1996

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**Transformation**

‘Storytelling is the mode of description best suited to transformation in new situations of action.’

Schön, 1988

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**Crises in healthcare**

- A team in crisis
- An organisation in crisis
- A global crisis

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**A team in crisis**

‘Culture is the way we do things when no one is looking.’

Professor Tricia Hart, CEO
James Cook University Hospital

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**The problem**

- Very sick patients
- Not enough beds
- Not enough staff
- Not enough time
- Poor management
- Records in disarray
- Medical model of care
- No one listens
- Culture of fear

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**What staff said**

‘I would not want a member of my family nursed on this ward.’

‘I dread coming to work. I hate it here.’

‘I check the off-duty to see who I am working with.’

‘I had no assurance that patients were safe; I felt helpless, hopeless and powerless.’ (Senior nurse)
What families said

'I continue to see him in such pain, no one should die like that.'
'I want to meet all of those nurses and ask them why?'

Result:
93% of staff would not want their relatives cared for on the ward

A conventional response

Special measures
• Organisational Development Team
• New nursing leadership
• Honest conversations
• Holding the boundaries; Code of Conduct
• Staff engagement

A conventional response

• Move back to original ward
• Team nursing
• Move to more holistic model of care
• Appreciation
• Openness
• Focus on staff well-being

Result!

But...

‘The team was left in a dark place; a place of torn relationships, mistrust and broken spirits.’
‘The stories teams tell each other are their lifeblood.’
Amy Stabler, OD lead

A radical response

A digital storytelling project intended to:
• provide closure on a difficult experience
• support the development of emotional resilience
• deepen a culture of care and compassion
• develop a learning resource for others in the organisation
• provide qualitative data to help with evaluating the experiences of the ward team
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Impact on storytellers

‘It’s helped me get a lot off my chest – I’ve put it to bed now.’
‘I didn’t realise how sad everyone was.’
‘I’m still angry, but making the story helped me process those feelings and I’m not as angry now.’
‘I feel like we’ve learned a lot about each other’s stories that we didn’t know before. This has brought home what the ward means to everyone.’

Impact on staff

Impact on patients

‘I’ve been looked after so well here – and not just by one person, but by everyone!’
‘All the staff here are so kind.’
‘We wanted to take him home but he was too ill, but he was looked after like a prince. Thank you.’

Impact on the ward

97% of staff would now be happy to have their family cared for on the ward
An organisation in crisis

‘If there is one lesson to be learnt, I suggest it is that people must always come before numbers.’

Robert Francis QC, 2010

Dignity and respect

‘Patients care more about being treated with dignity and respect than they do about mortality rates.’

Ben Page, 2004

The problem

Poor patient and staff satisfaction survey scores, especially in relation to dignity, respect and communication

A radical response

Create a bank of stories that would:
• complement and enhance training around dignity, respect and privacy
• focus on dignity as expressed through empathy, compassion and sensitivity
• contribute to an online educational resource
• encourage staff to engage with the affective (emotional) dimension of care

Why digital stories?

• put healthcare professionals into the shoes of a patient or a carer
• help doctors, nurses, accountants, managers and board members to appreciate the impact of care from a personal perspective
• create an instant connection to the patient
• remind staff that kindness, compassion and dignity often make the biggest difference
What happened?

- 2.5 years
- 7 workshops
- 49 participants
- 53 stories created
- 40 stories released (to date)

Using the stories

- induction and staff training
- public screenings to raise public awareness of mental health

Using the stories

- shown at the start of every Board meeting
- used in recruitment and selection interviews

Using the stories

- strengthening the patient voice
- triangulating themes and trends
- within recovery networks and recovery education

Listen! Believe! Act!

Faye Larkin 2013

What the CEO said


Noted by Michelle Moran 5 March 2014 09:12

I was genuinely humbled by the courage of one of our digital patient stories at board this month. 'Listen, Believe, Act' told the story of someone who had felt unheard, shamed and unseen as she travelled through mental health services from her early teenage years to young adulthood. It was a really moving illustration of just how critical it can be to really listen, to believe what we hear and then to act upon it in good faith.

It is a lesson which applies to everything in life. This month, we heard at least some feedback around low levels of staff morale. Frustration and anxiety due to some of the service developments and improvements we have been trying to implement. It’s easy to think that much of this is due to uncertainty across the system and the challenging environment in which all our staff are operating. But, after the digital story, I realised that I needed to share www.bit.ly/voicesbelieveact. Let me know what you think.

Michelle Moran, 2014
What the CEO said

Michelle Moran, 2014

Impact: what’s changed

• patient-led ‘dignity walks’
• more confident patients and staff, able to tell their stories
• increased involvement of patients and carers in creation of care plans
• greater recognition of ‘experts by experience’
• more engagement with family members

Impact on quality

• Reduction in complaints related to care (45%)
• Reduction in complaints related to staff issues (9%)
• Reduction in complaints related to communication (22%)
• Reduction in CNST claims (50%)
• Reduction in management costs

A global crisis

• Malaria kills a child somewhere in the world every minute
• It infects approximately 219 million people each year
• estimated 660,000 deaths, mostly children in Africa
• Malaria accounts for one in six of all childhood deaths in Africa
• Malaria has serious economic impacts in Africa, slowing development and perpetuating poverty
A global crisis

Saying brains:
Long-term neurocognitive assessment of children following an episode of severe malaria: the artesunate suppository trial cohort

‘Within low resource settings, children with impairments are considered a family and social liability and seldom receive the resources needed to support their development.’

‘Outline for disseminating results from the research
“A neurocognitive assessment of Study 13 children”’

Burness Communications and Pilgrim Projects Limited June 2012

A traditional response

Give everyone a mosquito net!

A radical response

• involve patients and communities in the dissemination of their experiences and of the results of the research study
• enable children and parents affected by malaria to tell their own stories
• illuminate what it is like to live with a severe disability arising from childhood malaria
• form a plea for malaria control.

Insight

‘These stories allow us to walk in someone else’s shoes for a few minutes.’

A warning

‘Please control your emotions. These people don’t need your pity. They need your empathy.’
Rehema, 2014

**Reactions**

**Storytellers said:**
- ‘Three words: Like. Enjoy. Accept.’
- ‘There is no harm in sharing this story.’
- ‘I’m not just happy with it: it is beyond happiness.’
- ‘It exceeded my expectations – it is time well spent.’

**NIMR researchers said:**
- ‘There are many long term and short term measures on how to live with disability but perhaps these stories can also help to prevent malaria? How can we focus these stories so that they can be used as part of prevention and also provoke thought and discussion and debate?’
- ‘[This project] has brought people together in a community to share stories.’
- ‘I will 100% use these stories to influence policy-makers.’

**Possibilities**

‘I have consistently asked for the addition of some funds to capture the economic consequences of malaria. It is clear to me now, that some of these stories make the case for looking at the economic consequences of severe disease and sequelae far more powerfully than I can (or have!).’

Dr Melba Gomez
Principle Investigator, WHO

**Let us be radical!**

‘Narrative is radical, creating us at the very moment it is created.’

Toni Morrison, 1994
The stories are all one

‘Each affects the other and the other affects the next and the world is full of stories and the stories are all one.’

Mitch Albom, 2004

References


Thank you

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The Patient Voices stories can be seen at:
www.patientvoices.eu
@PatientvoicesUK