Hearing Voices: creating and using digital stories of mental health to promote dignity and respect, humanity and compassion in health and social care

Create Act Change
International Digital Storytelling Conference
Hacettepe University
Ankara, Turkey

9th May 2013

Who are we?

Pip Hardy, Director, Pilgrim Projects/Patient Voices, Cambridge, UK
Tony Sumner, Director, Pilgrim Projects/Patient Voices, Cambridge, UK
Henri Rahman, Carer
Dave Williams, Carer and Head of Manchester Carers Forum
Dr Carol Haigh, Professor of Nursing, Manchester Metropolitan University, Manchester UK
Patrick Cahoon, Head of Patient Experience, Manchester Mental Health and Social Care Trust

Why are we here?

• The scenario of mental health is dismal across the world.
• In the UK, one in four people will experience mental illness.
• The prospect of dementia looms large.
• Stigma and discrimination lead to persistent suffering, disability and economic loss through violation of human rights.
• Mental health care is often lacking in dignity and respect.

Why are we here?

‘Patients care more about being treated with dignity and respect than they do about mortality rates.’
Ben Page 2004

Aims of the project

• create a bank of stories to enhance and complement training and education around dignity, respect and privacy.
• focus on dignity as expressed through empathy, compassion and sensitivity
• develop an online educational resource
• enable staff to engage with the affective (emotional) dimension of care
• encourage reflection on impact of care that promotes dignity

What happened

Carol and Eula

Chris
What happened

Anne Brenda and Dee

What happened

Dawn Lindsey

What happened

Bob’s story

Part of the world again

www.patientvoices.org.uk/flv/0586pv384.htm

Your thoughts?
Good stories are

• Effective
• Affective
• Reflective

Sumner, 2008

Brenda’s story

Freedom

www.patientvoices.org.uk/fly/0643pv384.htm

The Story behind the stories

Why

Carol Haigh
What I expected

What I didn’t expect

Looking to the future....

Thank you for your attention

Contact me on: c.haigh@mmu.ac.uk

Henri

Henri’s storyboard
Henri’s story

Labour of love

www.patientvoices.org.uk/flv/0596pv384.htm

Henri’s reflections

Your thoughts?

Dave

Dave’s story

Just for today

www.patientvoices.org.uk/flv/0651pv384.htm
No man is an island, 
Entire of itself. 
Each is a piece of the continent, 
A part of the main.

John Donne

Your thoughts?

Patrick

Patrick’s reflections

Why digital stories? 
• putting healthcare professionals right into the shoes of a patient or a carer 
• helping doctors, nurses, accountants, board members to really experience and appreciate the impact of that care from a truly personal perspective 
• creating an instant connection to the patient 
• reminding staff that kindness, compassion and dignity often make the biggest difference

Patrick’s reflections

How the stories are being used: 
• shown at the start of every Board meeting 
• used in recruitment and selection interviews 
• induction and staff training 
• public screenings to raise public awareness of mental health 
• strengthening the patient voice
Patrick’s reflections

Themes:
• strength and resilience
• isolation
• importance of communication
• lack of dignity and respect
• lack of care co-ordination
• need for more and better information

Patrick’s reflections

Themes:
• need for empathy and compassion
• need for regular assessment and review
• need for greater involvement in decision-making
• importance of self-help and peer support
• importance of voluntary sector
• needs of carers

Patrick’s reflections

What’s changed?
• patient-led ‘dignity walks’
• more confident storytellers, able to get their message across
• increased involvement of patients and carers in creation of care plans
• ‘experts by experience’
• more engagement with family members

Hopes for the future

• storytelling in hard-to-reach communities
• raising awareness of the stories
• use of stories in recruitment
• more stories for the Board!
• more staff stories
• collaborative research into potential for transformation and culture change.

Thank you.

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Distribution of the Patient Voices digital stories is funded by www.pilgrimprojects.co.uk