Cultivating compassion in care: the power of stories

Pip Hardy

Pilgrim Projects / Patient Voices

Cultivating compassion evaluation conference. Brighton, UK
6th May 2015

www.pilgrimprojects.co.uk

©2015 Pilgrim Projects Limited

www.patientvoices.eu

Patient Voices

patience, noun. calm endurance of pain or any provocation; perseverance

patient, adj. having or showing patience

voice, verb. give utterance to, express

Concise Oxford Dictionary, 1964

Patient Voices: what we set out to achieve

‘...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.’

We hope that, as a result of seeing the stories, patients, their carers and clinicians may meet as equals and work respectfully together for the benefit of all.’

Patient Voices Rationale 2004

Patient Voices: some facts and figures

- Established in 2003
- ~1000 stories facilitated/recorded
- ~600 stories released
- ~130 workshops, plus some home visits!
- ~15 Patient Voices stories WIP
- ~1 million hits on the website annually
- ~2000 hits per working day on PV website
- ~40,000 stories viewed during the year
- ~100 presentations
- 6 papers published
- 1 book published

Patient Voices: where we work

[Insert world map with workshops]

Patient Voices: suffering

[Images of people]
The pursuit of healthcare

Relief from suffering

Relief from suffering...

‘To the typical physician, my illness is a routine incident in his rounds, while for me it’s the crisis of my life.’

Relief from suffering?

‘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

Relief from suffering: the art

• Intuition
• Kindness
• Understanding
• Communication
• ‘Soft’ skills
• Respect
• Tenderness
• Compassion
• Stories and Narrative Based Medicine

Professional and compassionate

Langfjord 2012
Professional and compassionate

This story is not released for the website.

Time to reflect: EAR

Effective
Affective
Reflective
Summer 2009

Compassion

‘The whole idea of compassion is based on a keen awareness of the interdependence of all these living beings, which are all part of one another, and all involved in one another.’

Thomas Merton

Compassion

‘The quivering of the heart in the face of sorrow, pain or suffering.’

Jack Kornfield

Compassion

‘Compassion is not a relationship between the healer and the wounded. It’s a relationship between equals. Only when we know our own darkness well can we be present with the darkness of others. Compassion becomes real when we recognize our shared humanity.’

Pema Chödrön

Stories and compassion

‘Telling, sharing and hearing stories is another way of crossing the boundaries of consciousness, opening our hearts and cultivating compassion for all beings as if they were part of our family.’

Kornfield 2008
Transforming culture

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

Schön, 1988

Markers and guides

‘Every light was a story and the flashes themselves were the stories going out over the waves, as markers and guides, comfort and warning.’

Winterson, 2005

The care of the patient

‘One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.’

Francis Peabody (1927)
The care of the patient

Relieving suffering

‘Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest complement, or the smallest act of caring, all of which have the potential to turn a life around.’ Source unknown

Night shift

Vaitkunas 2013

Cultivating compassion

Creating the right conditions:
- Preparing the ground
- Sowing the seeds
- Nurturing the plants
Preparing the ground

- becoming aware
- noticing the nature of suffering
- tolerating uncertainty and ambiguity
- accepting ourselves
- being kind to ourselves
- recognising our interconnectedness

Sowing the seeds

- cultivating skilful action
- developing wisdom
- offering kindness
- relieving suffering
- sharing joy
- practising equanimity

Ways of knowing

- Empirical knowing
- Aesthetic knowing
- Personal knowing
- Ethical knowing
  Carper 1978

Nurturing the seeds

Making and taking time

- time to notice
- time to reflect
- time to care
- time to listen
- time to breathe
- time to ‘just be’

Creating the right conditions

Creating space

- temenos (sacred space)
- deep listening
- story circles

Self-compassion

‘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
Ubuntu: the essence of being human

‘The solitary human being is a contradiction in terms and therefore you seek to work for the common good because your humanity comes into its own in belonging.’

Archbishop Desmond Tutu

Xenia: the art of hospitality

‘We are guests in our patients’ lives; and we are their hosts when they come to us. Why should they, or we, expect anything less than the graciousness expected by guests and from hosts at their very best?’

Berwick 1999

The man in Bed 5

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

Medical Officer, National Institute of Medical Research, Dar es Salaam, Tanzania

Walking in someone else’s shoes

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

Medical Officer, National Institute of Medical Research, Dar es Salaam, Tanzania

Walking in someone else’s shoes

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

Medical Officer, National Institute of Medical Research, Dar es Salaam, Tanzania

The culture of the mind...

‘The culture of the mind must be subservient to the culture of the heart.’

MK Gandhi
What if all the people who could not sleep
at two or three or four
in the morning,
left their houses
and went to the parks?
What if there were
thousands, millions,
went in their solitudes
like a stream
and each told their story?
What if there were
old women
fearful if they slept
they would die
and young women
unable to conceive
and husbands
having affairs
and children
fearful of failing
and fathers
worried about paying bills
and men
having business
and women unlucky in love
and those that were in physical
pain and those who were guilty?
What if they all left their houses
like a stream
and the moon
illuminated their way and
they came, each one
to tell their stories?
Would these be the more troubled
of humanity?
Or would these be the passionate of this world
or those who need to create to live
or would these be
the lonely ones?
And I ask you
if they all came to the parks
at night
would the sun on rising
be more radiant and
again I ask you
would they embrace?
— Lawrence Tirnauer

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.’
— Albom 2004