

effective
affective **Voices**
Patient
reflective

Digital
Storytelling
in a
Crisis

Raising Voices

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Pilgrim Projects/Patient Voices National and Kapodistrian University of Athens, 8th May 2014

Raising Voices


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A reflective and reflexive look at the interdependencies of crisis, injustice, voice, storytelling, justice and facilitation!

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Crisis and injustice

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Crisis, what crisis?
Injustice, what injustice?

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Injustice and healthcare

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'Of all forms of inequality, injustice in health care is the most shocking and inhumane.'



Martin Luther King Jr, 1966

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Justice and voice

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'Justice is not identical with the good life as such. Rather, social justice concerns the degree to which a society contains and supports the institutional conditions necessary for the realization of... values essential to the construction of the "good life":

- 1) *developing and exercising one's capacities and expressing one's experience, and*
- 2) *participating in determining one's action and the conditions of one's action.'*

Iris Marion Young, 1990

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The need to speak

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She thinks of Carlos, of Margaret, of Jimmy.
She thinks of her father, and of her mother.
She thinks of all the women she has been, of all the men.
She thinks of the color of her skin, and of Chicago streets, and of waterfalls and pines.
She thinks of moonlight nights, and of cool spring storms.
Her mind chatters like neon and northside bars.
She thinks of the 4 a.m. lonelineses that have folded her up like death, discordant, without logical and beautiful conclusion.
Her teeth break off at the edges.
She would speak.

Joy Harjo, 1983

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How are you?

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David Gill, 2014

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How are you?

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<http://www.patientvoices.org.uk/flv/0778pv384.htm>

David Gill, 2014

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Not being heard

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'...it didn't feel like they were the teachers and we were the pupils; suddenly we were a small group of interesting, diverse and unique people sat in a room each with different experiences and opinions. But it really felt like our opinions, as students were greatly valued – this (perhaps unfortunately) is something that is relatively unusual when one studies medicine. We get used to being told exactly how things our; these are the facts, this is the law, this is how you treat someone – sometimes we forget that our own experiences and opinions are important.

What a refreshing experience it was to have it feel that our supervisors were even in very small ways learning from us in the same way we were learning from them.'

David Gill, 2014

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Epistemic injustice

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'A wrong done to someone specifically in their capacity as knower'

Miranda Fricker, 2007



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Testimonial injustice

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'...occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word...'

Miranda Fricker, 2007

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Hermeneutic injustice

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'...occurs at a prior stage, when a gap in collective resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences.'

Miranda Fricker, 2007

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It's the art

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Gerry Third, 2011

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It's the art

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<http://www.patientvoices.org.uk/flv/0550pv384.htm>

Gerry Third, 2011

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The injustice within?

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Danger of facilitators taking or being seen to be in an epistemically privileged position because of their real (or perceived!):

- Training
- Skills
- Expertise
- Objectivity

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The injustice within?

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Whose story is it?
Permissions and releases
Copyright and distribution
Barriers to participation:

- Technological
- Physical
- Intellectual
- Language
- Cultural
- Access

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Testimonial justice

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Hear all the voices:

- Seek out and recognise the stories of all storytellers in the group
- All the stories have their own relevance
- Acknowledge that epistemic authority of each storyteller is inherent in their story and its telling

- Reflexive Facilitation

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Reflexive facilitation

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- 1 What am I feeling about this storyteller?
- 2 What similarities and differences affect this interpersonal situation?
- 3 How does my own ideology affect this workshop?
- 4 What group(s) outside the workshop am I identifying with?
- 5 Why am I facilitating this workshop in the first place?
- 6 In selecting storytelling prompts and offering editorial suggestions (textual/visual/audio), what alternatives could I have employed and why did I reject them?
- 7 What are the effects on me as I facilitate this story?
- 8 How do my reactions to the story affect my facilitation?

Tony Sumner (2014) adapted from Valerie Yow, 1997

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Hermeneutic justice

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Address disadvantage:

- Appropriate technology
- Amended workshop scheduling
- Adequate levels of facilitation support
- Access
- Interpretation services

- Adaptive Facilitation

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Adaptive facilitation

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People with early stage dementia
www.patientvoices.org.uk/dc.htm

Increased facilitator numbers (one to one).
Reduced daily hours (three hours per day, over four days).
Facilitators as chauffeurs, driving computers under guidance of storytellers.
Adapting print of scripts to match ability to follow sentences on page, size of print, one sentence per sheet, etc.
Recording scripts one sentence at a time.
Using 'contact prints' of images on paper for image selection by storyteller, rather than on screen.
Facilitators 'holding the thread' on behalf of the teller of a story that may diverge in an almost fractal fashion.
Setting workshop in a familiar physical environment.
(Stenhouse, Tait, Hardy, & Sumner, 2012)

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Adaptive facilitation

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Elderly (ages 72-102) storytellers in care home setting
www.patientvoices.org.uk/hc.htm

Increase facilitator numbers.
Technology 'chauffeurs'.
Use of PA/'karaoke' machine by facilitators and in story circle to aid the hard-of-hearing and the quiet of voice.
Large print of scripts for reading/recording.
(Hardy and Sumner, 2014)

People with disabilities (blindness, Asperger's, quadriplegia, learning disabilities, etc., re-entering employment
www.patientvoices.org.uk/exdra.htm

Use editing software that can be driven by assistive technologies (speech input, drop-switches, on-screen keyboards, head-tracking mouse pointers).
(Hardy and Sumner, 2014)

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Adaptive facilitation

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People with stroke
www.patientvoices.org.uk/iowsc.htm
www.patientvoices.org.uk/naoconn.htm

Scheduling workshop for six hours a day, one day a week over four weeks.
Minimal writing – use of photos as prompts to record small segments of script at a time.
Plenty of encouragement to 'take your time' for people with aphasia
(Hardy and Sumner, 2014)

Kosovan refugees
www.patientvoices.org.uk/newham.htm

Setting workshop in 'safe' environment of community centre
Provision of interpreter support
Allowing a significant break at lunch time for storytellers to create and facilitators to share, traditional food and hospitality
(Hardy and Sumner, 2014)

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Adaptive facilitation

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Rheumatoid arthritis sufferers
www.patientvoices.org.uk/wr.htm

Adapt schedule to match energy profiles of storytellers:
two hours am, two hours pm for four days.
Plenty of nourishing food!
(O'Neill and Hardy, 2008)

Carers
www.patientvoices.org.uk/sheffcc.htm
www.patientvoices.org.uk/sheffcc2.htm
www.patientvoices.org.uk/hcr.htm

Provision of respite care.
Shortened days to allow travel.
(Hardy and Sumner, 2014)

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Our hope - and challenge

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In these terms does more justice
always mean less injustice?

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Looking back...

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On reflection, how did we do in 2006?

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New beginnings

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Emmanuel Godis, 2006

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New beginnings

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<http://www.patientvoices.org.uk/flv/0068pv384.htm>

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Thank you

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