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

Crisis and injustice

Crisis, what crisis?
Injustice, what injustice?

Injustice and healthcare

‘Of all forms of inequality, injustice in health care is the most shocking and inhumane.’
Martin Luther King Jr, 1966

Justice and voice

‘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

The need to speak

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. loneliness 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
How are you?

Not being heard

"...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

Epistemic injustice

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

Miranda Fricker, 2007

Testimonial injustice

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

Miranda Fricker, 2007

Hermeneutic injustice

‘...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
The injustice within?

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

- Training
- Skills
- Expertise
- Objectivity

Whose story is it?

Permissions and releases
Copyright and distribution
Barriers to participation:
- Technological
- Physical
- Intellectual
- Language
- Cultural
- Access

Testimonial justice

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

Reflexive facilitation

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
Adaptive facilitation

**Hermeneutic justice**

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

- *Adaptive Facilitation*

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**Adaptive facilitation**

People with early stage dementia

- 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.
- Adequate facilitation levels per session.
- Access
- Interpretation services

- *Adaptive Facilitation*

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**Adaptive facilitation**

Elderly (ages 72-102) storytellers in care home setting

- Increased facilitator numbers.
- 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*

**Adaptive facilitation**

People with disabilities (blindness, Asperger’s, quadraplegia, learning disabilities, etc., re-entering employment

- 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*

**Adaptive facilitation**

People with stroke

- Setting workshops 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*

**Adaptive facilitation**

Kosovan refugees

- Setting workshops in ‘safe’ environment.
- Provision of interpreter support.
- Allowing significant break at lunch time for storytellers to create and facilitators to share, traditional food and hospitality.

- *Hardy and Sumner, 2014*

**Adaptive facilitation**

Rheumatoid arthritis sufferers

- Adapt schedule to match energy profiles of storytellers: two hours am, two hours pm for four days.
- Plenty of nourishing food!

- *O’Neil and Hardy, 2008*

**Adaptive facilitation**

Carers

- Provision of respite care.
- Shortened days to allow travel.

- *Hardy and Sumner, 2014*

In these terms does more justice always mean less injustice?
Looking back...

On reflection, how did we do in 2006?

New beginnings

Emmanuel Godis, 2006

New beginnings

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

Thank you

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www.patientvoices.eu

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References