

Benefits and challenges of participatory research methods

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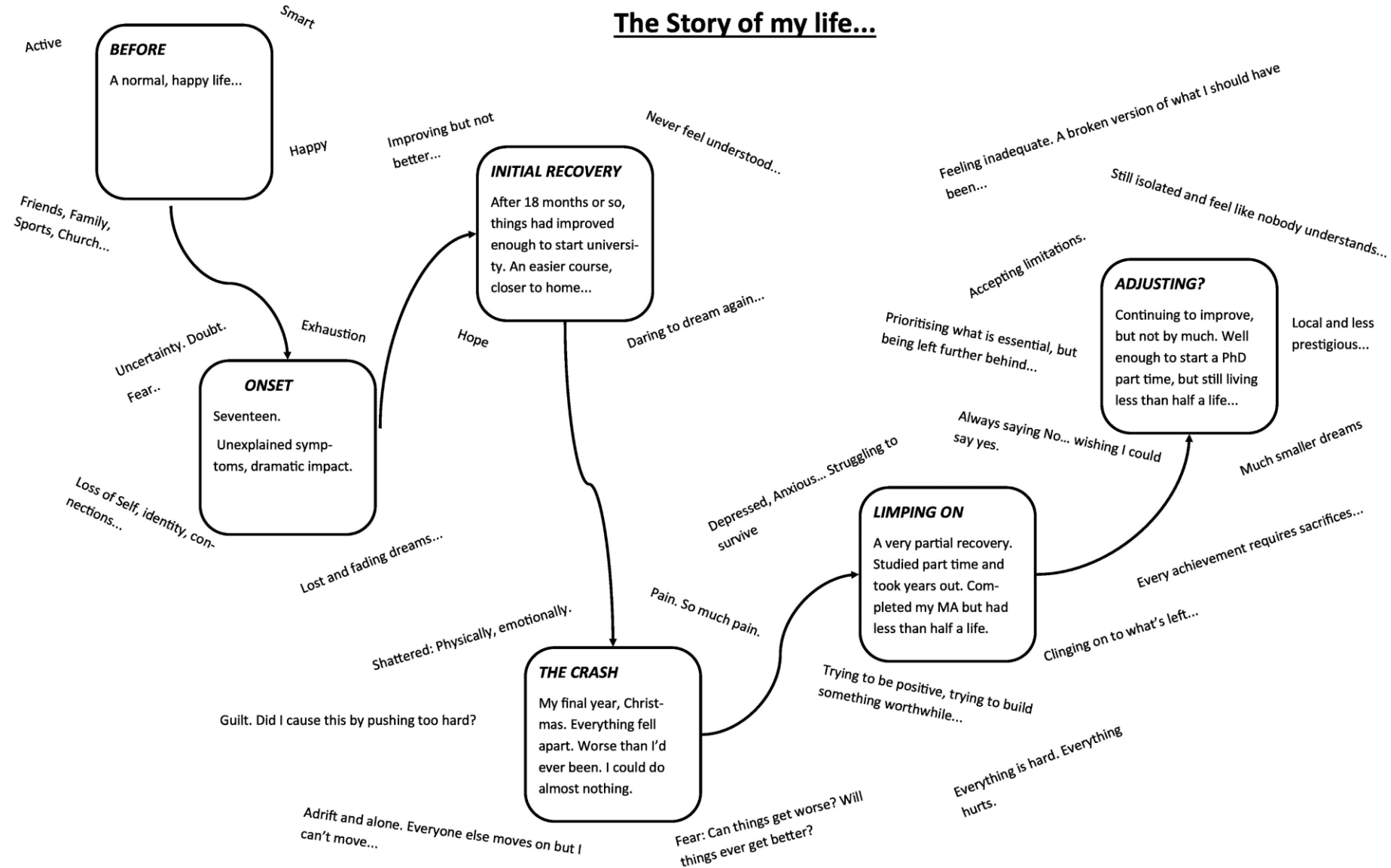
Participatory and creative research

- Power differentials between researcher and researched
- Getting closer to experiences
- Richer data: photo elicitation, journaling, photo/video diary

Fibromyalgia and academic identity



The Story of my life...







Strong coffee to wake up, b4 work

Drowsy from the meds



more money spent on meds and creams



Harvard Square





I DON'T WANT TO DIE WITHOUT A VOICE

Charlie is only 29 but she's dying. She has motor neurone disease.

MND is fatal and before they die people are trapped in a failing body. It kills 5 people every day in the UK. Half within just 14 months of diagnosis. Before it kills Charlie it will steal her speech, but she still has plenty to say. Hear Charlie's story and how the MND Association is helping her, and thousands like her have a voice.

Visit www.mndassociation.org/charlie to donate £5 text MND VOICE to 70004

mnda
motor neurone disease
association









3 cornerstones of human understanding and communication

- a) human understanding is embodied (Finlay, 2015)
- b) language is insufficient and inexact (Scarry, 1985; Sontag, 2003)
- c) communication and human understanding are metaphorical (Lakoff and Johnson, 2003)

From: Brown, N. (2019). Identity boxes: using materials and metaphors to elicit experiences. *International Journal of Social Research Methodology*, 22 (5), 487-501.

Analysing data from creative, participatory methods

- **Which framework?**
- **Value and validity of interpretations**
- **Is there a solution?**

Horsebridge Open 2018

Art is Something Much More Dangerous

13 - 28 January



I need duvet days

Shattered. Broken.

Numb. Empty.

Physically, and emotionally.

It's very invisible.

I am sick all the time.

I'm fed up with it, and I'm
trying to live my life without it.

But it's getting worse.

My brain is working but my body can't do it.

It started in one bit of my body and now other bits of my body follow.

I can be as well as possible and with a full life.

But I think of myself as a perpetual patient, as disabled.

It isn't how I thought my life was going to be.



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