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The coconut day: the lived experience of seizure Consciousness

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British Psychological Society.

Qualitative Methods in Psychology Conference (QMiP)

Conference Theme: 'Making a difference, making ourselves
known'

Hosted by the University of Huddersfield
September 2013.

Symposia title: Phenomenological consciousness and
extremes of human experience

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The coconut day: the lived experience of seizure
Consciousness

*Val Featherstone, Peter Campion and Anna Sandfield with
Vince and Dave.*

- ‘no counterpart in ordinary human experience’ (Johanson, Valli et al., 2008)
- Epileptic and non epileptic seizures
 - Phenomenological quality of consciousness
- Awareness of cognitive processes over time

“What is most true is poetic. What is most true is naked life. I apply myself to ‘seeing’ the world nude.”
Cixious, (1997) in (van Manen, 2006)

Diamond Cutting. Poems;

- Are all based on empirical data
- Use images and metaphor participants produce
- Include compression, and positioning of words
- Distil the essence of the experience economically

It could be the case that self-expression through art is an underused tool in neurology.
Stafstrom, (2005)

Art work

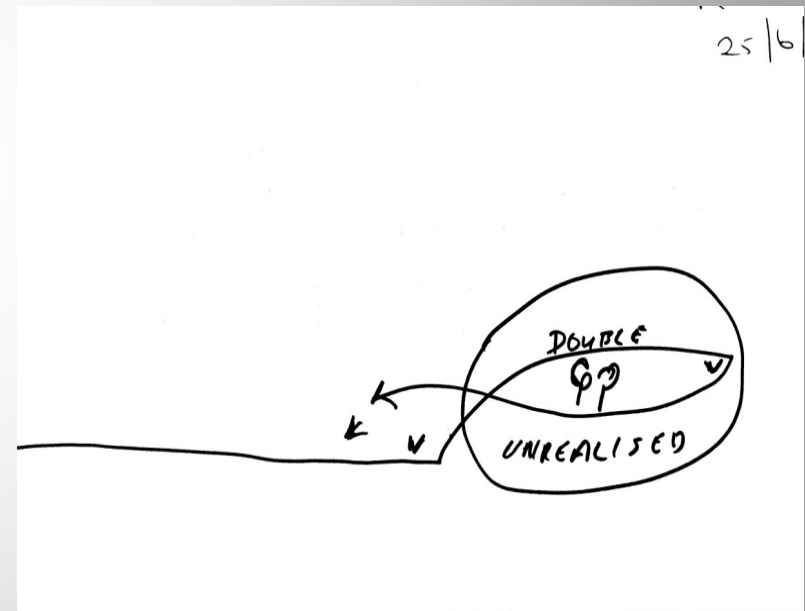
- leaves visual traces of lived experiences
- depicts unique, difficult physical experiences offering insights into relationships between subjective experiences and external environments
- offer information about the artist, meanings, resources available to them
- One phenomenological moment

"It was all—to draw it, all it would be would be a question mark. Yes, a question mark—because, it is something I so definitely don't understand so what exactly is happening is totally questionable. Yeah, and that is the obvious question mark and to say it goes back as far as where I had the brain damage in the car accident, yes."

Vince

"I'll let you try and work that that out—even though that looks like a fish"

"The whole circle around that there that's me—questioning going in, questioning coming out. But still ... mmm, still unrealised because you don't really feel and if you don't really feel, then the realisation is minimal. No the realisation is, if you feel exactly what is going on—but you don't, so that makes it unrealised. Well that's probably why it's so bloody confusing. You are going in with something and you are coming out and other people realise you have gone in—you come out without any real realisation."



“Going funny”

Drawn away the company I was talking to, this feeling of being with - but totally
apart from

I was there but, indeed, I wasn't
I seemed to be totally removed
I have become epileptic

When I came back I knew I'd been - it almost felt as I'd had been somewhere else
I hadn't been *there*
But when I came back I realised that I hadn't left
I had become epileptic

As I pulled away, I seemed to be suspended
I could see the people I was talking to, but the *contact* seemed to be broken
I seemed to have been taken away
I had become epileptic

The contact I was making, even though I could still see, the contact with them was no longer there
I was *trying* to speak but it was mumbo jumbo
The contact had been broken
I had become epileptic

Because I failed to realise just what was actually going on
And I couldn't understand the reality of why
He isn't there, he's gone
He has become epileptic

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Shifts in conscious state

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- Movement from dynamic to static state
- Illusions of being somewhere else
- Autoscopy (OOB experiences)
- Coenaesthasias (sensations of migrating, movement, lightness, levitation, elevation.
- Extraordinary visual, auditory, tactile and motor experiences
- Differences in self awareness

Not losing consciousness completely

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Phenomenological qualia



**The experiential properties of sensations, feelings, perceptions, thoughts and desires.
(Monaco, Mula et al., 2005)**

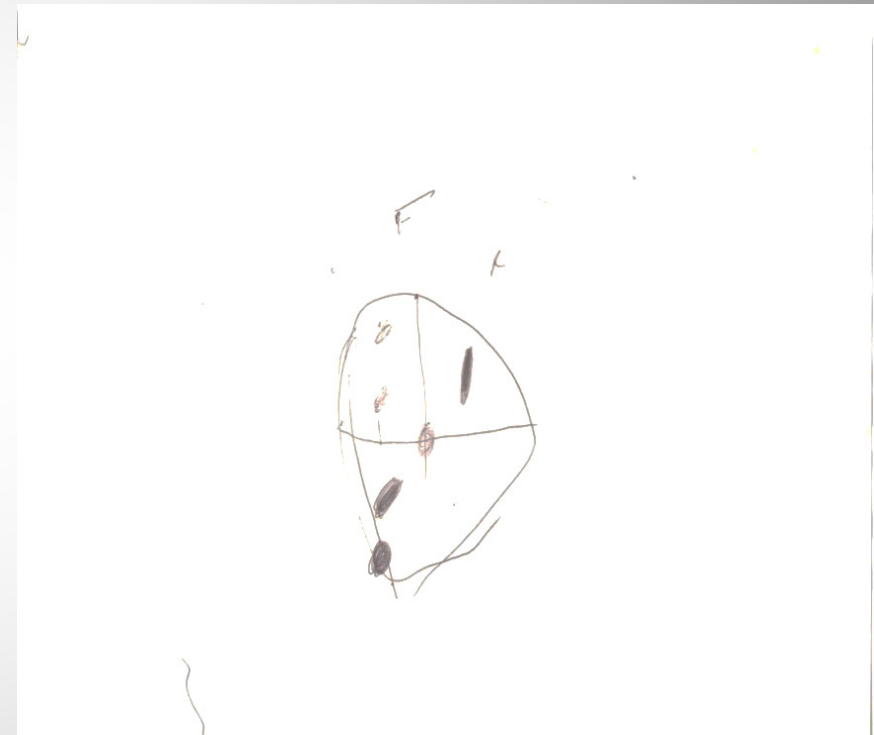
Making sense of someone's lived experience is not 'rule bound' but rather, a 'free act of 'seeing', and a process of 'insightful invention, discovery and disclosure' and this cannot always be captured in 'conceptual abstractions (van Manen, 1998)



What it feels like in my brain

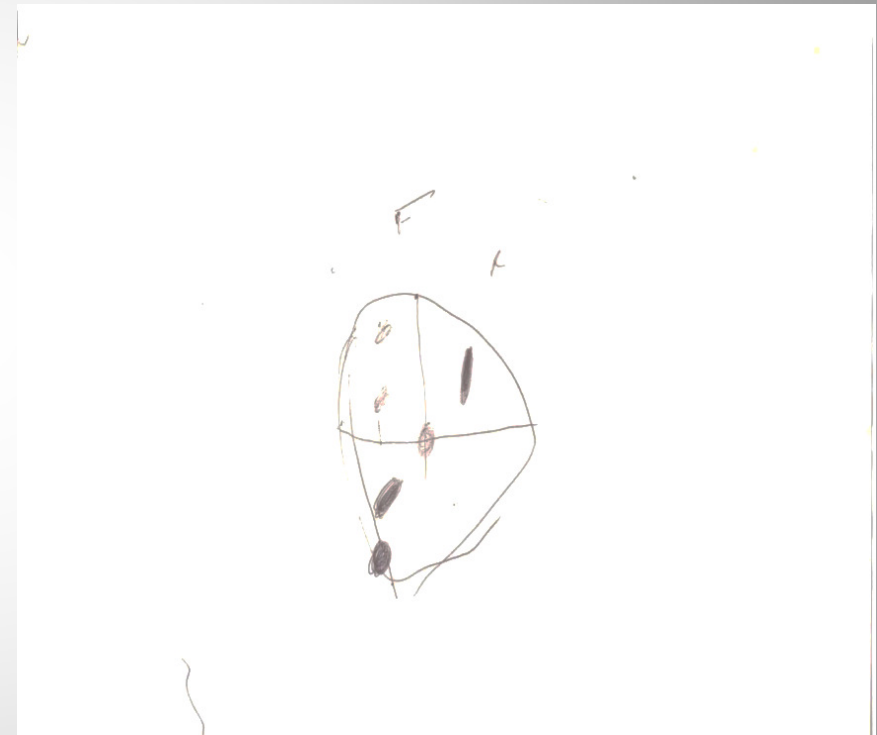
Divide my head into quarters. That's me front , that's me right I get headaches there, I get headaches roundabout that area and that area - these are *intensities*, like the darker it is, the more intense the pain *can* be. It doesn't mean that it *is* going to be *that* intense, but that's how it *can* be intense. Er, er and there ... Headaches and pains, that there could be lower back, sort of there.

This part, this part here, there, seems to be the only part of my head that seems to be unaffected. That seems to the only part of my head that seems to be unaffected, there—seems to *feel*? Seem to have something at the time.



What it feels like in my brain

I think I'd be ooh, ooh sort of erm
...more stupider erm, more like I said that's
sort of – one quart less intelligent. Yeah—
one quart less intelligent



Auto pilot – I am in auto pilot

"me brain just seems to turn off and I can walk around.

"So I'd ran through it in me 'ead, what I was gonna do ... so I've gone onto automatic and actually done it. The next thing I remember is being stood on the middle of a road looking at a lorry coming towards me. You see, the trouble is I've got no memory in the gaps. I've tried to remember what I did, I've zero, zilch. There's only the clues of the potatoes. So I've done somethink , must have done somethink to there".



Dave: Abnormal functional shifts in attention and information processing



- Dissociation experiences
- Interference with perceptual, cognitive and attentional processing
- Undertaking complex behaviours without conscious awareness
- Clinically significant distress

Retaining some cognitive consciousness which allowed him to save his life



But er another worrying thing is the black outs.
Yeah, it may not be a fit but - me brain just seems to turn off and I can walk around.

Not know where I am.
Not know where I've been.
Not know what I've done.

I started to feel rough like something's pressing down, pulling down my head or whatever.
It's like being in a football crowd and everybody's screaming at you for attention but you're not able to respond to any of them.
It's basically em, how can I put it? Em, half awake, half asleep and this part - that's where the scream's coming from.

I knew I wanted a couple of onions and a bag of potatoes.

The next thing I remember is being stood on the middle of a road looking at a lorry coming towards me.

Unfortunately, I'd stopped right bang smack in the middle of Beverley Road looking at this lorry coming towards me.

I don't know.
I just came to.

I can move like a rocket when I want to!

Ah, but this is a weird one - carrying a bag of potatoes, yeah.

Autopilot.
I'm in auto pilot.
I'm in auto pilot.



“The coconut day”

How can I put it - the coconut day
The coconut day, yes

When I have my little day dreams where things, where I’m walking, or whatever
When I went out for some food, well I went out for milk, something to eat

I noticed the day previous, I noticed you know
I noticed the day previous - coconuts 60p

I went out with three quid, walking down the street and I had me rucksack on
Anyway, I gets home, thought never occurred to me
I gets home, and guess what’s in me rucksack

Five bloody coconuts
Five bloody coconuts
Five bloody coconuts

It still bugs me now
How on earth do you walk into a shop to buy five coconuts
How do you do it

Well, I mean
Obviously I do....

**Not only do we not know what we know,
but we do not know that we do not know** **Petitmengin (2006)**



Extending first person experiences

Exploring the pre-reflexive” would present “a rich and largely unexplored source of information and data with dramatic consequences

(VARELA AND SHEAR, 1999)

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The Coconut Day: A Poetic Interpretation of Seizure Experiences

Valerie A. Featherstone & Anna Sandfield