

SICSS Edinburgh Summer School

When Counting and Modelling is Not Enough: Case Studies from Health Research

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Learning Outcomes

- ❖ Understand how qualitative approaches can improve validity of computational social science
- ❖ Appreciate ethical issues in computational social science research on health

Speaking as an Expert by Experience



Outline

- ❖ Scene Setting
- ❖ The Role of Qualitative Research
- ❖ Human in the Loop
- ❖ Digital Exclusion

Scene Setting

Who has one of the following on their phones?

- ❖ Meditation app
- ❖ Yoga app
- ❖ Exercise / fitness app
- ❖ Mood tracker app

What Social Media Platforms are you on?

- ❖ Twitter
- ❖ Facebook
- ❖ Snapchat
- ❖ LinkedIn
- ❖ Instagram
- ❖ Other

Have you Shared Information about Your Own Health Issues?

- ❖ Yes, about physical health issues
- ❖ Yes, about sexual / reproductive health issues
- ❖ Yes, about mental health issues
- ❖ No
- ❖ That's an intrusive question, and I don't want to answer

Classic Application of Computational Social Science to Health

- ❖ Detect (mentions of) health issues / symptoms
- ❖ Detect (mentions of) social determinants of health (e.g., food insecurity, housing issues)
- ❖ Estimate geographical spread
- ❖ Track time course

The Cost of Getting it Wrong

- ❖ False alarm - symptom / health issue is detected, but not present
 - ❖ Distress of wrong information
- ❖ Miss - symptom / health issue is present, but could not be detected
 - ❖ Does the person want their symptoms / health issues to be detected?
 - ❖ Is detection in the person's best interest?

Useful Concepts (Corbin & Strauss 1985)

- ❖ Everyday life work: What has to be done to live one's life and function in society
- ❖ Illness work: What has to be done to address health issues and mitigate their effects
- ❖ Biographical work: What has to be done to integrate the health issues into one's concept of self

<https://link.springer.com/content/pdf/10.1007/BF00989485.pdf>



@chadwickboseman - died of colon cancer, mocked for weight loss

[–] to [/r/reddit.com](#) sent 10 minutes ago

New Help Center report has been received.

Report details: - Report Reason: It's targeted harassment at me


URL: `https://www.reddit.com/message/messages/1c5s9fg`
[Message]

Custom Text: Abuse of Reddit Cares

[permalink](#) [source](#) [reply](#)

https://www.reddit.com/r/SquaredCircle/comments/tr11z7/meta_how_to_report_potential_redditcares_abuse/

Comorbidities: One account, several issues

 lioness--hart

Depression: No do thing. Tired.

Me: Okay well. Maybe if I go to sleep super duper early, I'll get a decent amount of sleep.

Insomnia: You Fool. You absolute goddamn idiot

 lioness--hart

Insomnia: You Are Awake.

Me: Okay well. Maybe now I can get some stuff done.

Depression: You fool. You absolute goddamn idiot

Further Points to Consider

- ❖ Self-Care after detection may be difficult
- ❖ Diagnosis / detection does not equal access to treatment
- ❖ Treatment may not address root causes / may not work for this person
- ❖ Treatment suggestions may not be implementable

Policy Implications

- ❖ „Should society be making use of readily available, well-validated digital tools to detect and intervene to prevent self harm?“
- ❖ THESE TOOLS DO NOT EXIST.
- ❖ Research is based on instances where people who feel this way are comfortable with talking about it (mostly pseudonymously) on Western-centric social media, or on suicide notes
- ❖ THIS DOES NOT GENERALISE

The Role of Qualitative Research

How do you say that you are depressed?



northernwinedregs

Hi brain, you obstinate fucker. I drank the clear splashy stuff. I ate the green things. I went under that bright fucker up there. I did the thing with the moving and sweating and whatnot. Now make the happy chemical, you lump of fuck.

Source: northernwinedregs

How would a sentiment / emotion classifier classify this text?



northernwinedregs

Hi brain, you obstinate fucker. I drank the clear splashy stuff. I ate the green things. I went under that bright fucker up there. I did the thing with the moving and sweating and whatnot. Now make the happy chemical, you lump of fuck.

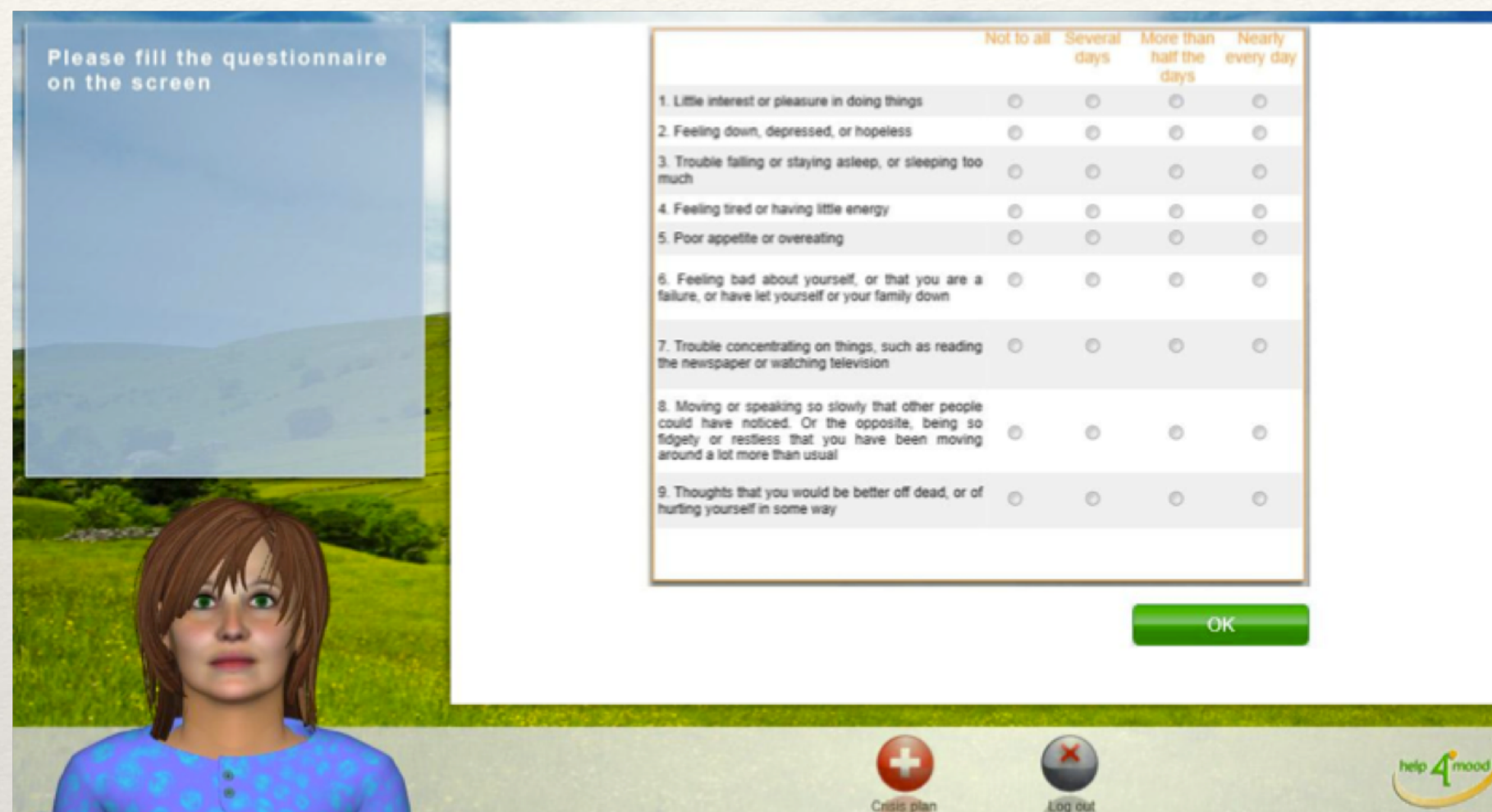
Source: northernwinedregs

Open Season: What do you know about qualitative research?

- ❖ Experiences
- ❖ Learned during summer school
- ❖ Towards deeper understanding of sensemaking

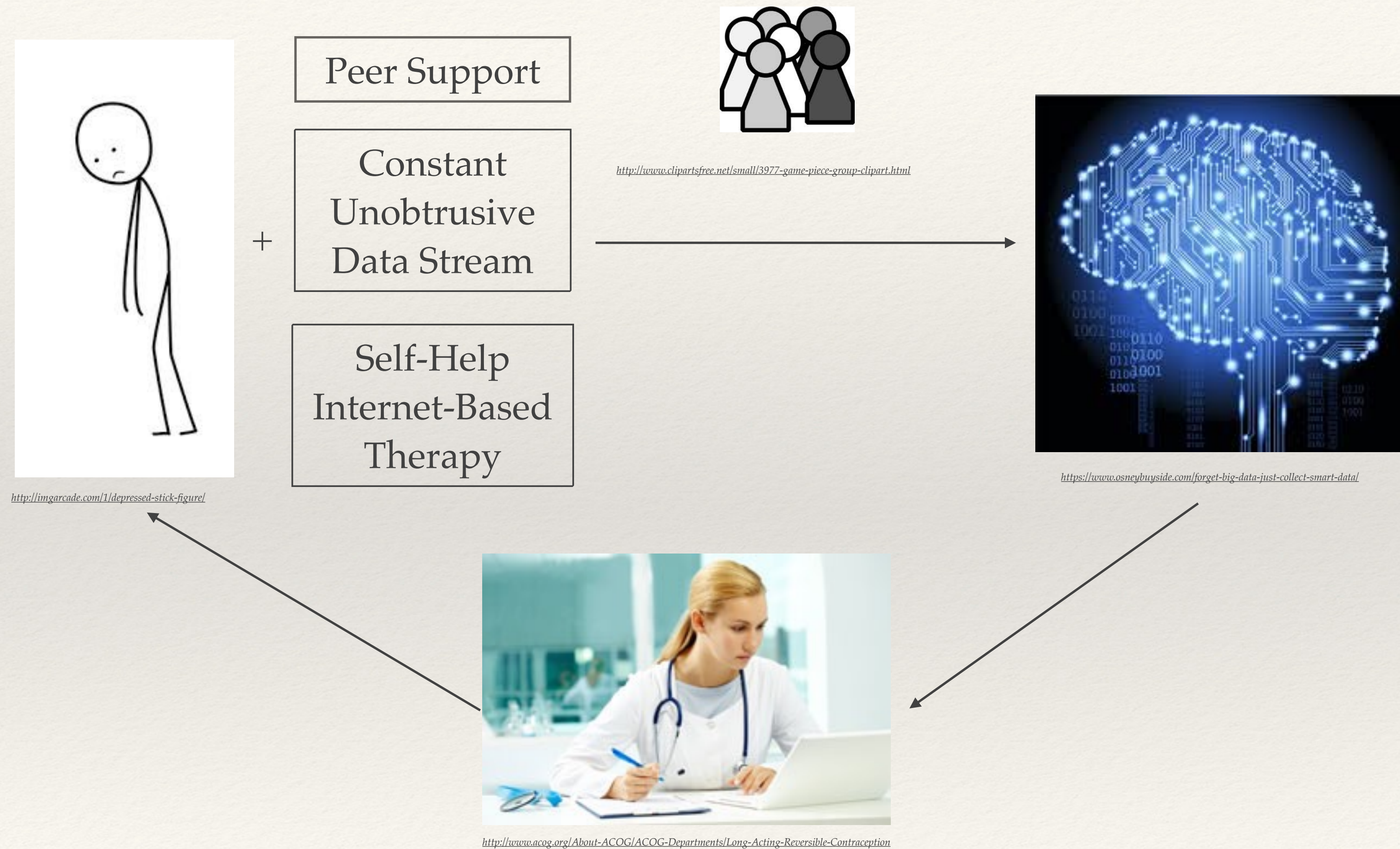
Human in the Loop

Help4Mood: Supporting People with Depression



- daily monitoring
 - of **activity** using actigraph
 - of **mood, thought patterns & psycho-motor** symptoms using talking head GUI
- weekly one-page reports to clinicians

It Doesn't (Quite) Work This Way



The Cost of Self-Reporting

“This wasn’t very pleasant.

Because you don’t go to therapy every day.

You wouldn’t go every day; you would go maybe once a week or two or three times maybe, but not every day.

It’s a bit too much to use it every day.”

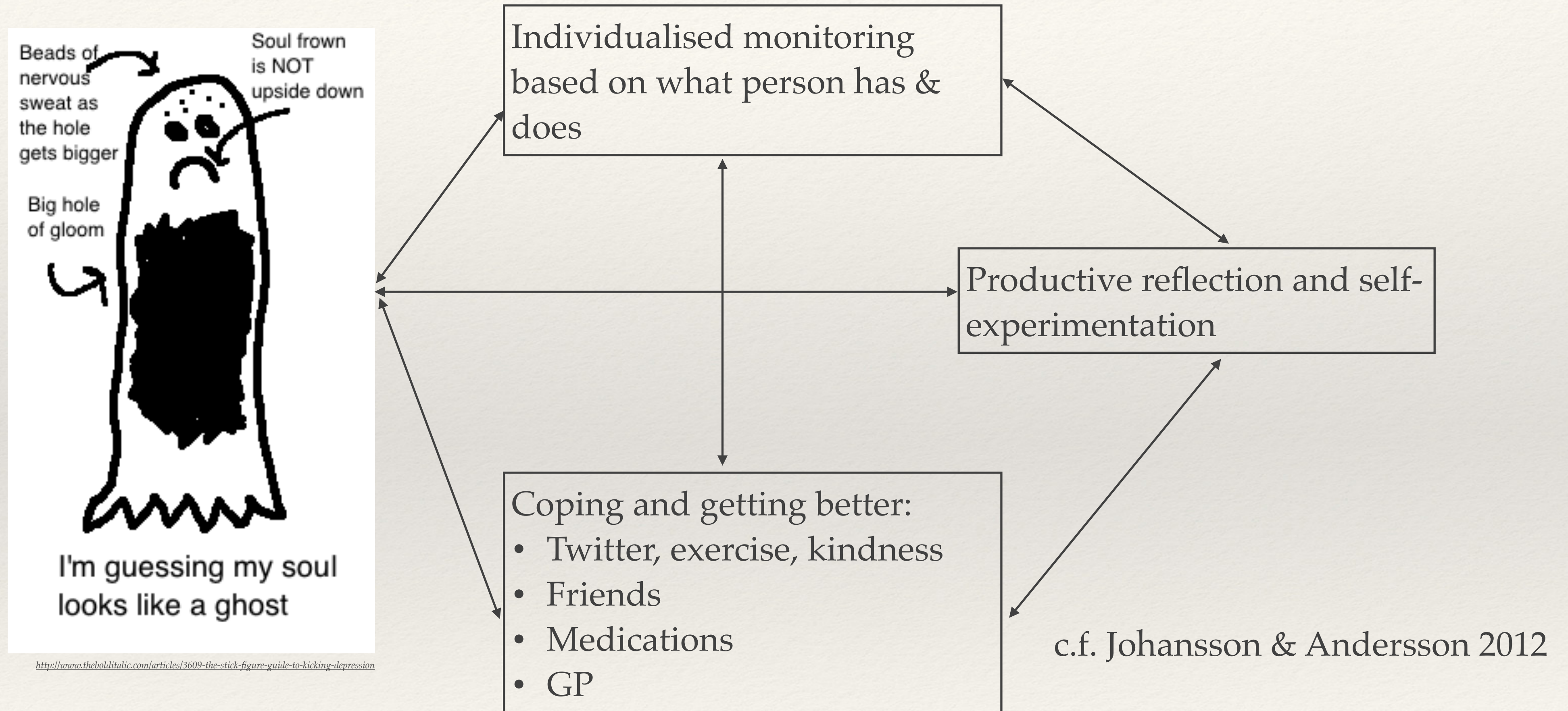
(P01, Case Studies)

Appropriation: Coping and Sensemaking

The monitoring part helped me understand some things [...] sometimes I did not realize how I felt that day, how happy I was or how active I was. The system helped me observe these things and also control them.

(RO14, female, 20–29)

It's a complex adaptive system



Digital Access



Who can afford a good smartphone with data?

Who can keep her phone charged?

Who has the energy to go on social media?

c.f. Greer et al. 2019

<https://www.dlbc.info>



Allie Brosh, Hyperbole and a Half

We Need to Understand the Context

- ❖ Who is in the relevant social network?
- ❖ What are relevant beliefs about technology use?
- ❖ What are relevant beliefs about privacy and stigma?

Questions?