

How to survive the end of the world (or at least of your own)

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ME ↓



2012: BA in Philosophy @ UniPD

2015: MA in Philosophical Sciences @UniPD

2017: International Research Fellow @RUB, Institute for Medical Ethics and History of Medicine

2022: PhD in Medical Sciences @UZH, Institute of Biomedical Ethics and History of Medicine

Ongoing projects:

- DIPEX data management
- Boosting Public Discourse: Towards a Targeted, Evidence-Based Strategy to Improve Moral Reasoning
- Pandemics & Bioethics: Co-Designing a Graphic Novel
- Scoping review background document for the WHO-convened ethics panel on ethical considerations of infodemic management, with a particular focus on social listening

Other fancy stuff:

TEDx speaker @Trento 2016

Scientific coordinator of Academia Engelberg 2019

Open Science Ambassador @UZH

Guest editor @ International Journal of Public Health

Reviewer for a bunch of journals (including Medicine, Health Care and Philosophy, PLOS One,

Reviewer for Public Health Ethics, JMIR, MHEP, ...)

Paragliding pilot and nerd, big fan of cows

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CAVEAT:

Possibly unhealthy mix of academic and personal stuff.



Should we *care*?

Disease, illness, sickness

The story I don't want to tell you

Evidence-based care

SUMMARIZING:

- Caring is different than curing
- You care a disease, you care for a person (bio psychosocial model)
- There's quite a knowledge gap about the subjective and social experience of working patients
- Search for: how long does it take to bring them care?
- Qualitative / mixed methods research could help filling knowledge gaps

Should we *care*?



CURE

- To cure: to heal or restore health; a treatment to restore health
(NIH National Cancer Institute dictionary)
- A therapy [...] is a treatment for a disorder or deficiency, which aims to bring an unhealthy person to health
(The President's Council on Bioethics, staff working paper on distinguishing therapy and enhancement, 2002)
- Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity
(WHO 1946)



CARE

- a species of activity that includes everything we do to maintain, contain, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment
 - Attentiveness, become aware of need;
 - Responsibility, willingness to respond and take care of need;
 - Competence, the skillset for providing good and successful care;
 - Responsiveness, consideration of the position of others as they see it and recognition of the potential for abuse in care
- (Joan Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care*, 1994)





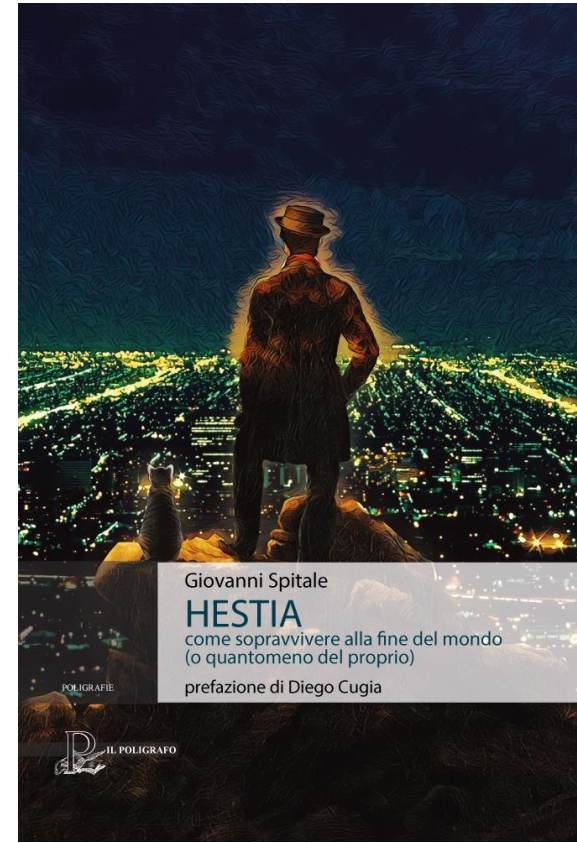






And that was the day. I arrived at the hospital with two suitcases of books and a stuffed cat, a pale surrogate for my three favourites. They numbered me, shaved my arms and punctured a few veins. I had a lot of people around me: my family, of course, then doctors, nurses, other patients... I never felt so alone, not even the time I climbed my first solo winter peak, with nothing but wind, rock and ice around me for kilometres.

At the exact moment when the bracelet with my name, number and barcode clicked into place, I realised that there are indeed moments when time stands still.



(Giovanni Spitale, Hestia, 2017)



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Disease, illness, sickness



DISEASE

- A pathological process, most often physical as in throat infection, or cancer of the bronchus, sometimes undetermined in origin, as in schizophrenia. The quality which identifies disease is some deviation from a biological norm. There is an objectivity about disease which doctors are able to see, touch, measure, smell. Diseases are valued as the central facts in the medical view

(Marshall Mariner, *Why make people patients?*, 1975)

(Kenneth Boyd, *Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts*, 2000)



ILLNESS

- A feeling, an experience of unhealth which is entirely personal, interior to the person of the patient. Often it accompanies disease, but the disease may be undeclared, as in the early stages of cancer or tuberculosis or diabetes. Sometimes illness exists where no disease can be found. Traditional medical education has made the deafening silence of illness-in-the-absence-of-disease unbearable to the clinician. The patient can offer the doctor nothing to satisfy his senses.
(Marshall Mariner, *Why make people patients?*, 1975)
(Kenneth Boyd, *Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts*, 2000)



SICKNESS

- The external and public mode of unhealth. Sickness is a social role, a status, a negotiated position in the world, a bargain struck between the person henceforward called 'sick', and a society which is prepared to recognise and sustain him. The security of this role depends on a number of factors, not least the possession of that much treasured gift, the disease. Sickness based on illness alone is a most uncertain status. But even the possession of disease does not guarantee equity in sickness.
(Marshall Mariner, *Why make people patients?*, 1975)
(Kenneth Boyd, *Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts*, 2000)



Idiopathic aplastic anemia.

I repeated these three words to myself for days, like a mantra, to strip them of their meaning and reduce them to pure sound.

Aplastic: soft and subtle like a D major chord played long and flat by a good violinist.

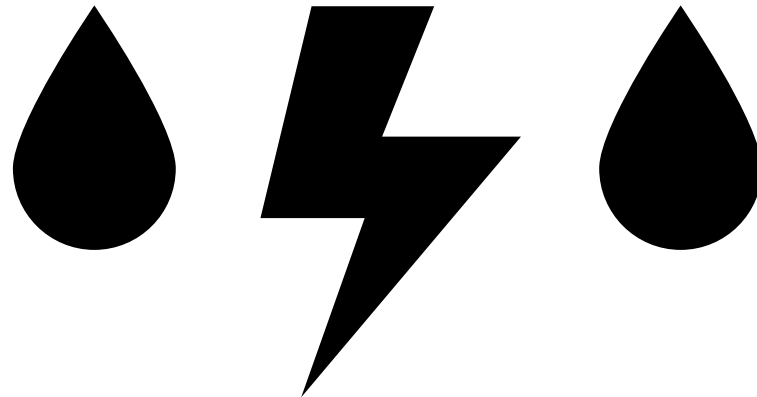
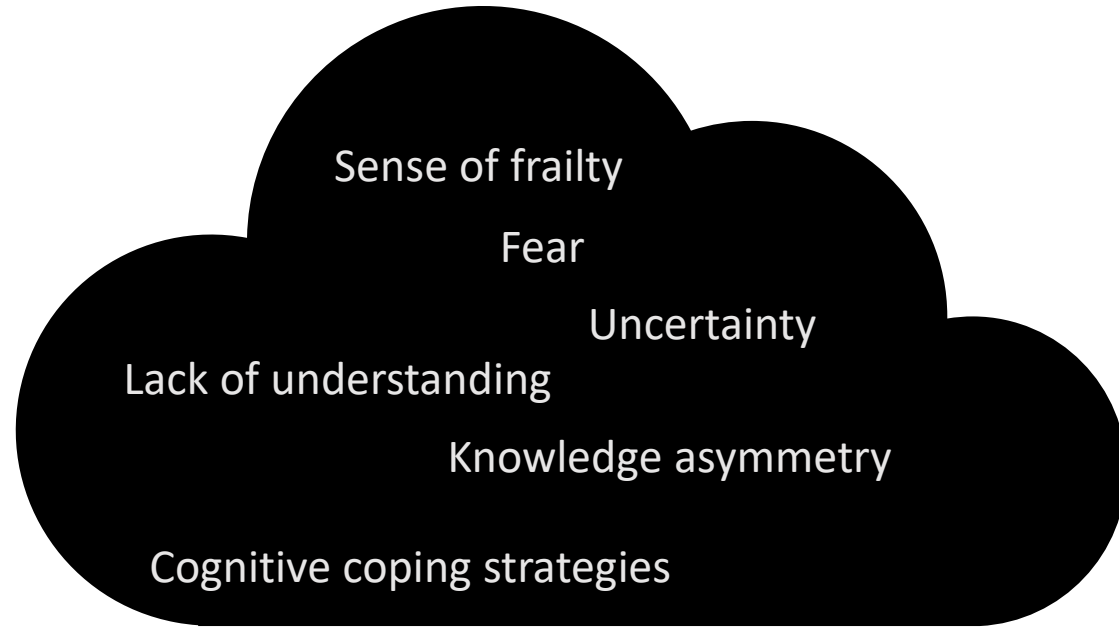
Anemia: G G G E, F F F D. Fate knocking at man's door, or at least the way Beethoven imagined it in his Fifth Symphony: something unexpected that takes you inside.

Idiopathic on the other hand tinkles, reminding me of Bach: the prelude number one in C major from the Well-Tempered Clavier. That, or a box of glasses breaking.

Obviously idiopathic aplastic anemia doesn't mean any of that, it's just the name of my disease, not musician's code. It is said that naming things makes them less scary, moving them from the realm of the unknown to the familiar; that sounds like a lot of bullshit to me. I was twenty-one and something that smelled like music and broken glasses wanted to kill me, crush all my dreams and shut me up forever. Nice gain, knowing the name: even if it had been called 'Sunday', nothing would have changed at all.



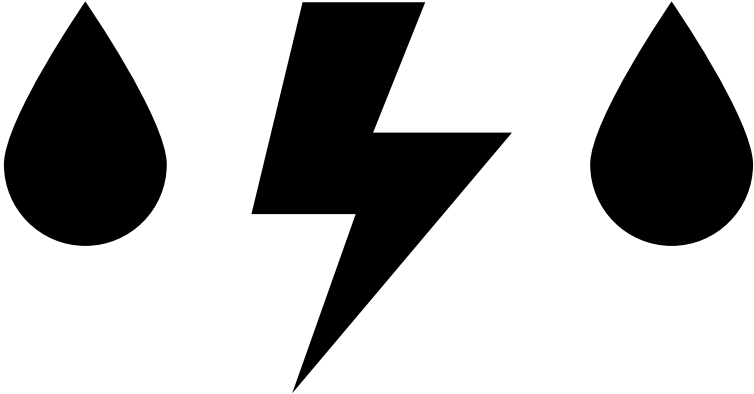
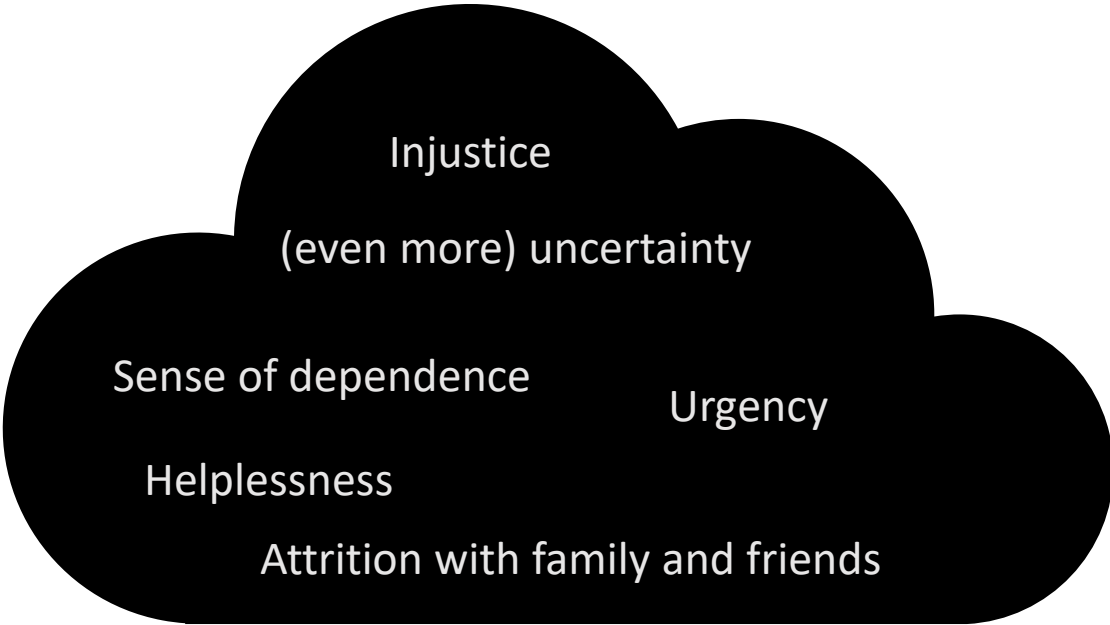


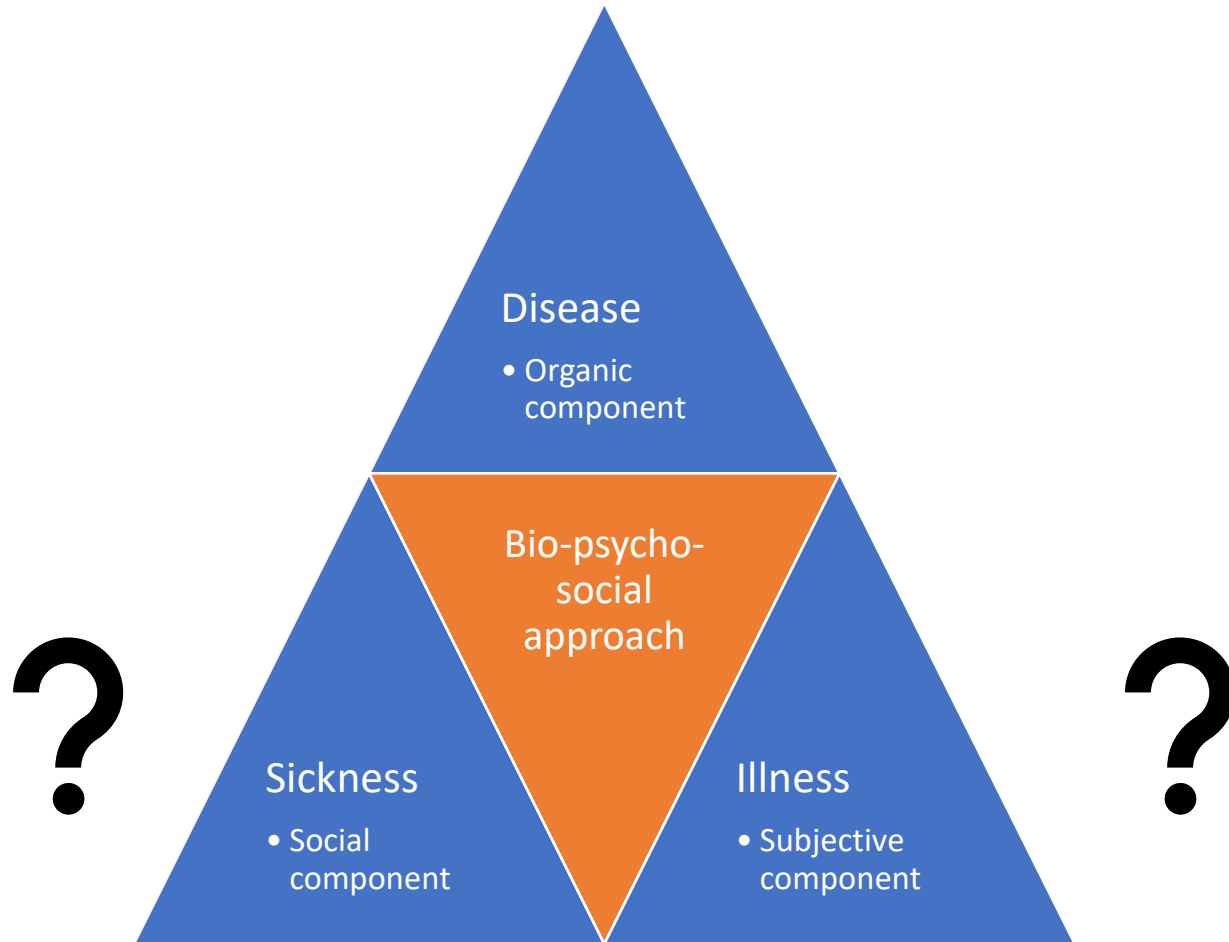




It is the numbers, the damn numbers, that make things so difficult for me and my fellow sufferers. On average, the odds of finding a compatible donor are one in a hundred thousand, you know. Then as if that wasn't enough you wanted to be a maverick and you have a very rare HLA, your 'compatibility code'. How rare? Rare, how to quantify it. In the bed next to yours a nineteen-year-old boy holds back tears as yet another test takes its toll, his pound of pain. Yes, but how much pain does it take to make a pound? Eh...Speaking of numbers: I'll be blunt and say that there are not enough people among 'you' willing to give a little of theirs to keep 'us' alive. There are a number of genuinely crazy elements in this story: for a start, it is crazy to have to come to terms with death at the age of twenty-two. But just take a trip to paediatrics to see worse. Then, this statistics thing is one of those that absolutely annoys me the most. If a hundred thousand of 'you' were to join the donor register after a blood test, I would probably find a person compatible with me among them. These are the numbers I rack my brains over, as I watch the drops slowly creep into my circulatory system. Then, tired, Giovanni, you decide to get up and take a walk in the corridor. How many like you do you meet? How many heads with sparse or missing hair, how many hollowed-out cheeks, how many sunken eyes? A hundred thousand for each of them.

(Giovanni Spitale, Hestia, 2017)





(George Engel, The Need for a New Medical Model: A Challenge for Biomedicine, 1977)
(Derick Wade and Peter Halligan, The biopsychosocial model of illness: a model whose time has come, 2017)



HOW CAN WE IDENTIFY AND ADDRESS UNMET NEEDS IN THE PSYCHO-SOCIAL AREA?

I.e.: how can we provide appropriate care (as in the *very utopian optimistic* WHO definition of health) to care for people's illness and sickness?

(I am just assuming that we all agree on one thing: these tasks do fall in the healthcare domain and should be a core part of a fair healthcare system, not a nice to have add-on)

The story I don't want to tell you



IT'S NEVER OVER.

The Institute of Medicine (IOM) published a report in 2005 suggesting the importance of integrating the patient into their survivorship care through treatment summaries and care plans. Several specific recommendations were made to: raise awareness among patients and providers, develop and use systematic evidence-based tools and guidelines for screening, develop quality measures for survivorship, support and develop new models of care coordination for survivors, educate health care providers, ensure access to affordable care and recognize survivorship care as an essential benefit in payment policies, and expand research. Despite these recommendations in a high-profile report, implementation of many of the recommendations has been very slow at best.

(Navneet Majhail and Douglas Rizzo, Surviving the cure: long term followup of hematopoietic cell transplant recipients, 2013)

In addition to medical complications, autologous and allogeneic HCT survivors are prone to sexual dysfunction, occupational disability, economic burden, negative body image and difficulties with social reintegration

(Navneet Majhail, Long Term Complications After Hematopoietic Cell Transplantation, 2017)



IT'S NEVER OVER.

You'll never be a former patient. You will keep struggling with your illness and your sickness for the rest of your life, no matter how good the outcome (of the disease treatment). It just becomes part of you.

Flashbacks, survivor's syndrome, healthcare avoidance, lack of meaning, optimistic nihilism, ...

My psychotherapist has somehow become a fan of mine&my demons 😊

Evidence-based care



Patient information

Anamnesis

Diagnostics

Individual preferences

Goals of care

Illness and sickness



Global evidence

Specific protocols

General guidelines

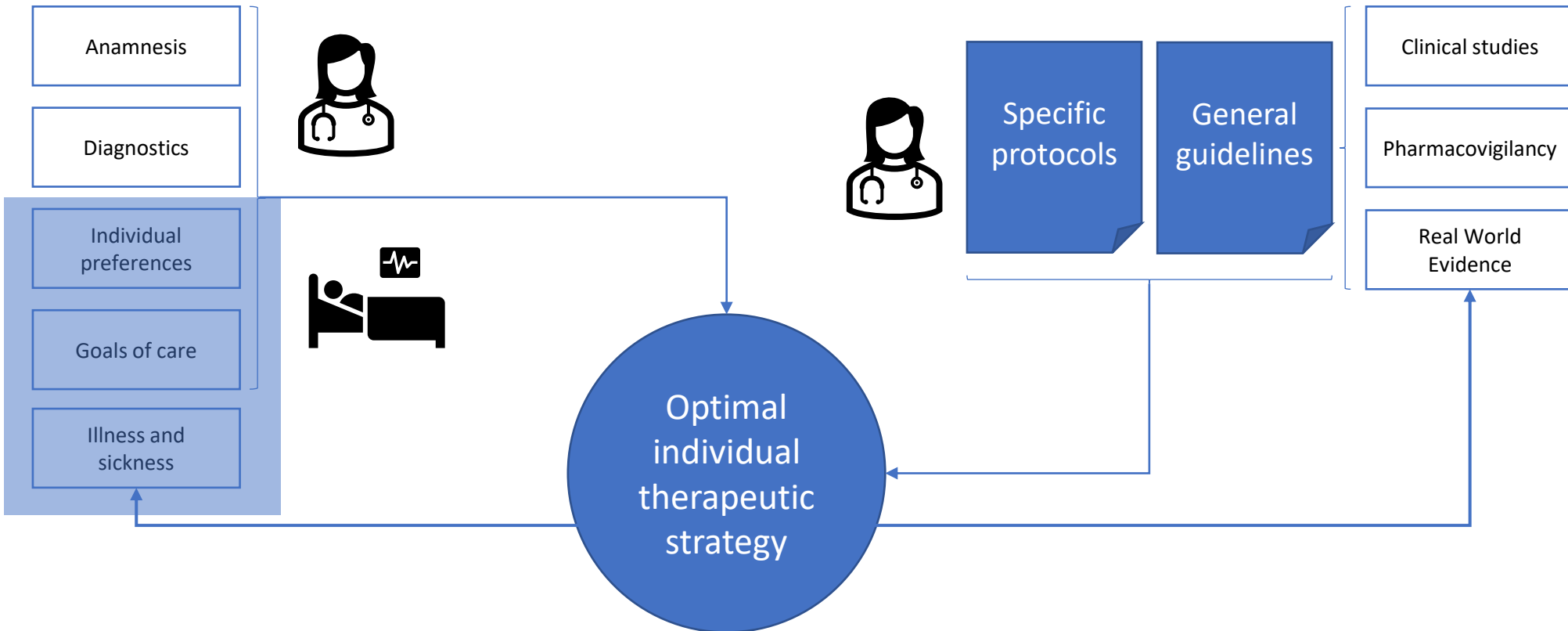
Clinical studies

Pharmacovigilancy

Real World Evidence



Optimal individual therapeutic strategy





Why not patient experiences?

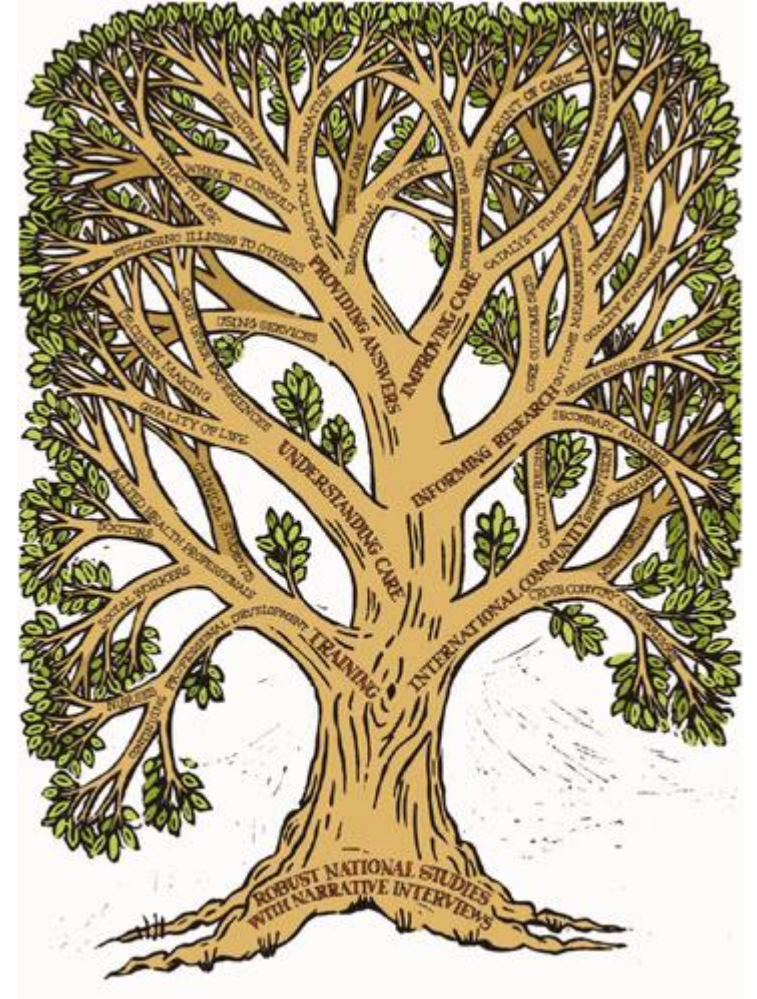
Ziebland, Grob and Schlesinger 2020, DOI: [10.1186/s12910-018-0304-3](https://doi.org/10.1186/s12910-018-0304-3):

- In 1999, general practitioner Ann McPherson (1945–2011) and clinical pharmacologist Andrew Herxheimer (1925–2016) shared the drive home from a conference which had featured the work of the Cochrane Collaboration. Comparing their own recent experiences of hospital treatments, they developed the idea for a public-facing database of people’s experiences of health, illness and care, as a complement to Cochrane’s assemblage of systematic reviews of evidence related to clinical outcomes. This led to the establishment of the DIPEX (Database of Individual Patient Experiences) project.
- DIPEX focuses on individuals, emphasizing the common themes and polyphonic perspectives on experiences within a health system. The DIPEX approach does this in three ways:
 - by seeking interviews with a wide sample of participants, from different backgrounds and locations, to maximize variation based on respondent attributes;
 - by asking about experiences in an open-ended way that allows for unexpected responses;
 - by interviewing people in their home and other settings that fosters participation by those less likely to give voice to their experiences via other channels.

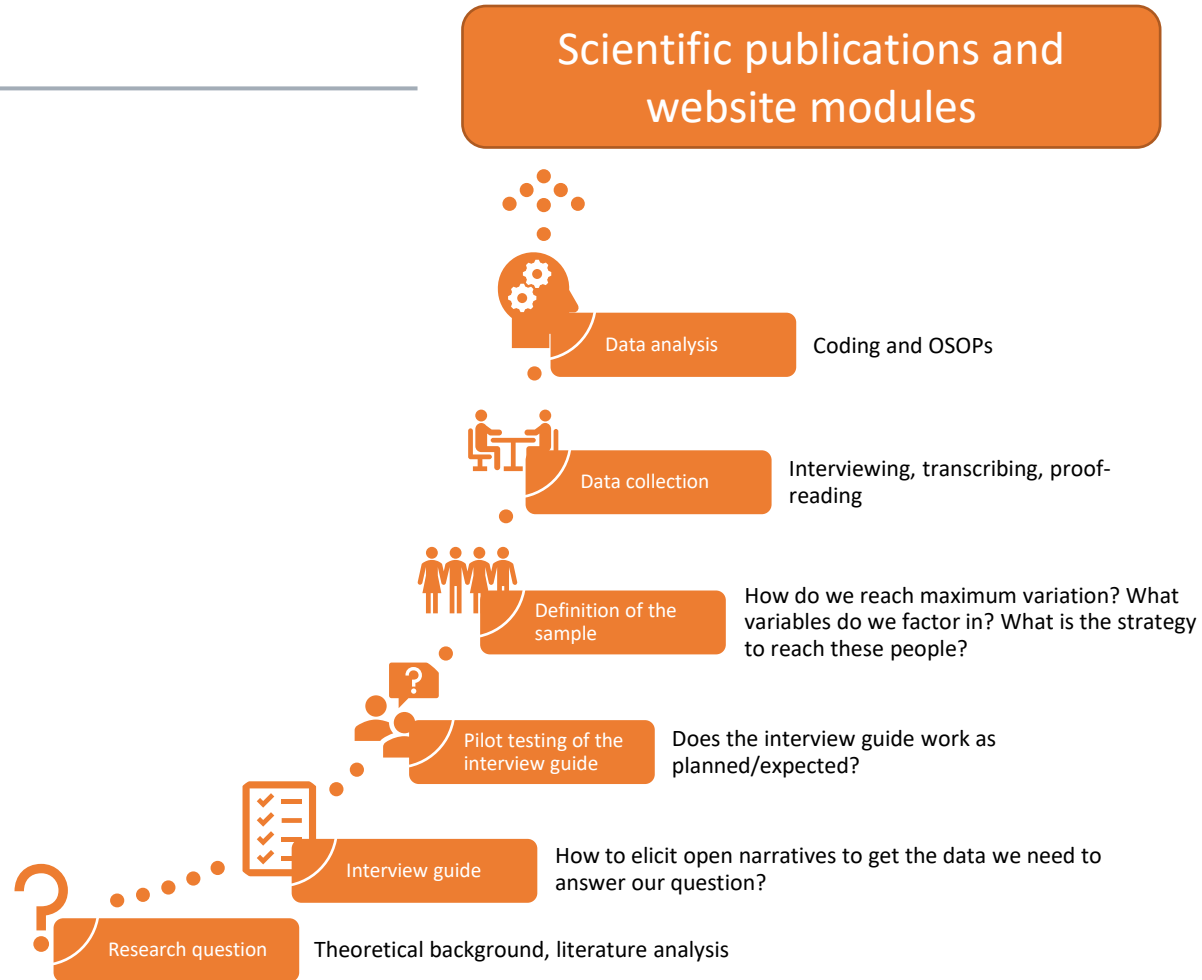
Our role, our responsibilities

“Of 4226 documents [on patient experiences], 17 studies met the inclusion criteria. The studies investigated 10 different sources of Web-based patient narratives. Sample sizes ranged from 23 to 2458. The mean score of the quality assessment was 82.6 (range 61-100). Effects regarding five different purposes were identified as follows: **provide information, engage, model behavior, persuade, and comfort.** We found positive effects in every category and negative effects in one category (persuade).”

(Drewniak, Glässel, Hodel and Biller-Andorno 2020)



The process in a nutshell



(Spitale et al. Patient narratives – a still undervalued resource for healthcare improvement, 2023)

Our role, our responsibilities

“Patients’ stories can change curricula and achieve a Trojan horse effect as they smuggle in, and make memorable, key curriculum points. Narratives can **engage the emotions**, developing and sustaining **interest**, which is so closely related to **motivation to learn.**”

(Ziebland, Grob and Schlesinger 2020)



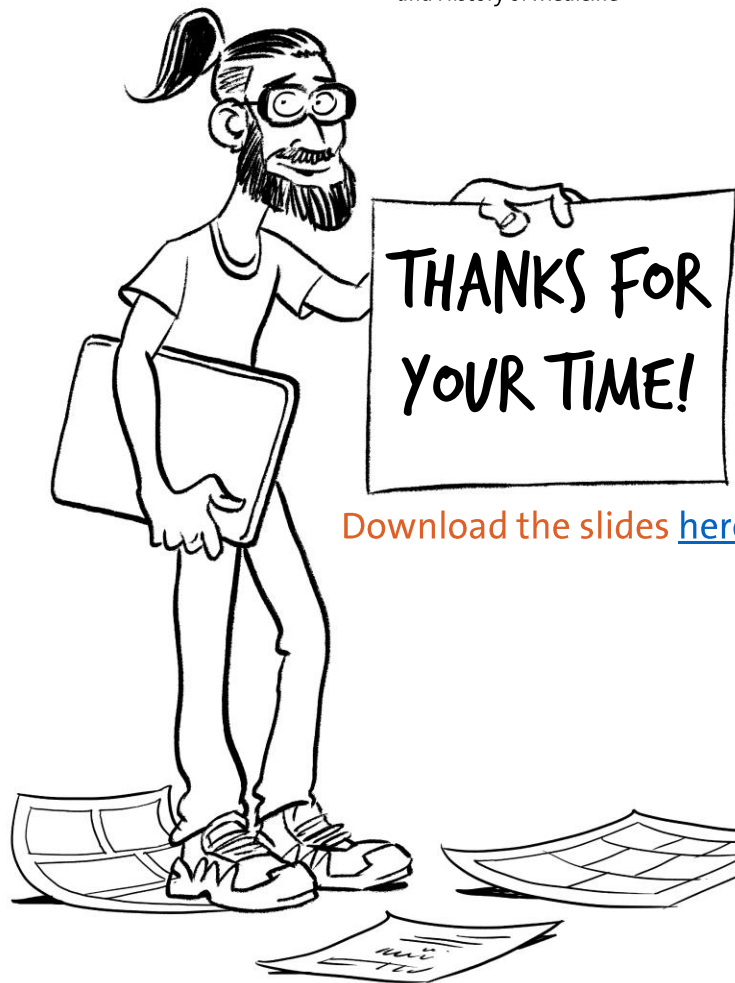
SUMMARIZING:

- Caring is different than curing
- You cure a disease, you care for a person (bio-psycho-social model)
- There's quite a knowledge gap about the subjective and social experience of waiting patients
- Same is true for long-term needs and long-term care
- Qualitative /mixed methods research could help filling knowledge gaps

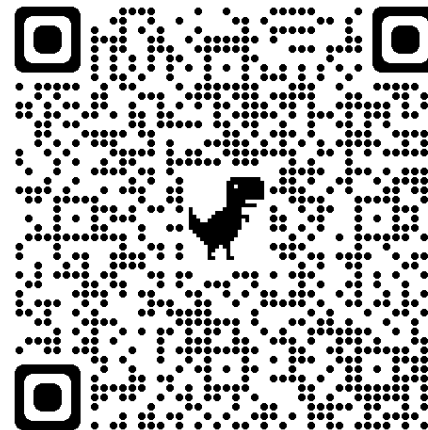


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BUCHE

IBME/Eric Buche