



@chapmanbe

## The varieties of healthcare experience: Pluralism, informatics, and consumer empowerment

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Brian E. Chapman, Ph.D.

A/Professor and Professional Patient





## A little bit about me...

- 4-time cancer survivor
  - Two childhood cancers (1976, 1983)
- 6 abdominal surgeries
  - 4 emergencies
- 4 orthopedic surgeries
- 2 “not-otherwise-categorized” surgeries
- Advanced peritonitis
- Gangrenous strangulated bowel
- And all the chronic issues that result from the acute ones!



My “mobile medical record”



## ...And

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- I have a PhD in Medical Informatics



## Abraham Heschel

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"Prayer is meaningless unless it is subversive..."







## ~~Abraham Heschel~~ Brian Chapman

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"A keynote is meaningless unless it is subversive..."





## “The Patient as a Person”

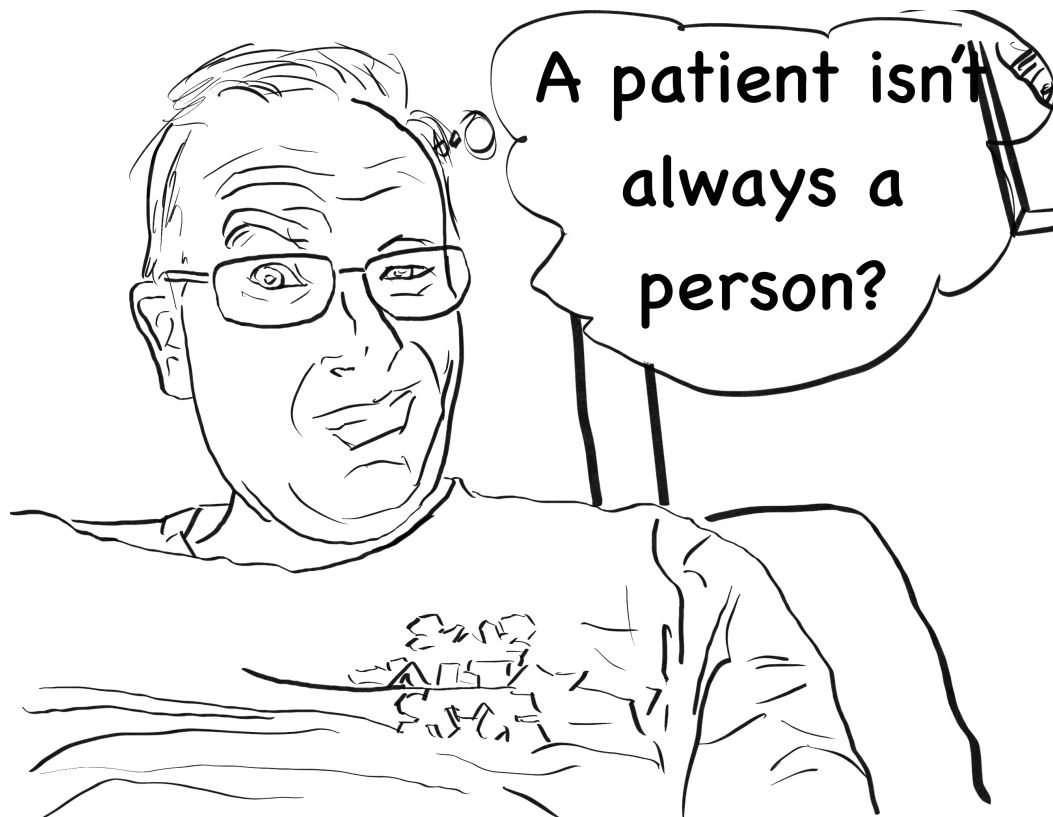
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- Part of the American Medical Association 1964 annual meeting in San Francisco
  - “physicians who plan to attend are encouraged to bring their wives, and doctors in the San Francisco area are also encouraged to invite their clergymen”
  - Abraham Heschel was invited to speak



**"I assert that  
every patient is  
in fact a  
person!"**





# MEDINFO23

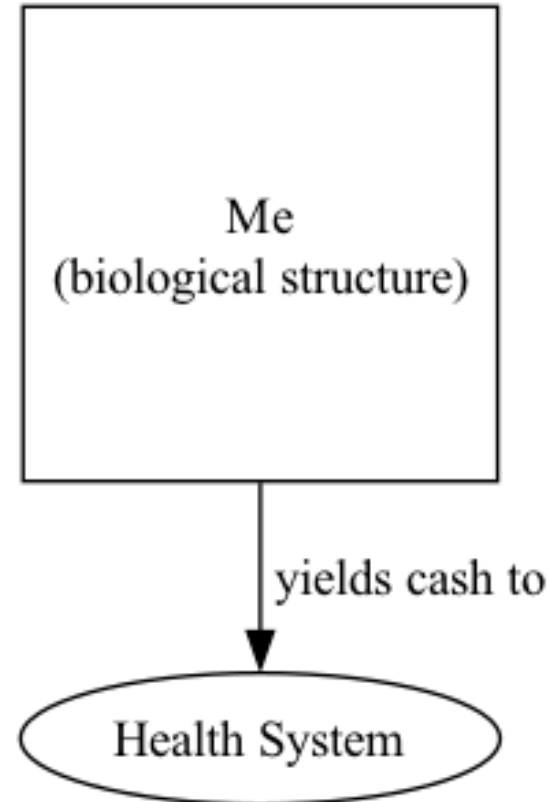
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## What is a patient?

- “A biological structure yielding cash”  
~ *Uwe Reinhardt*
- A system of interconnected physiological systems, each to be treated by a different specialist
- *A person (biological structure) who couldn't understand their medical care/record*







# Philosophy *Now*

a magazine of ideas

JES

CATEGORIES

TAGS

SHOP

**Question of the Month**

# What is a Person?



## What is a person?

- A being with
  - Imagination
  - Values
  - Agency (decision making)

**A being with epistemic needs and epistemic rights**



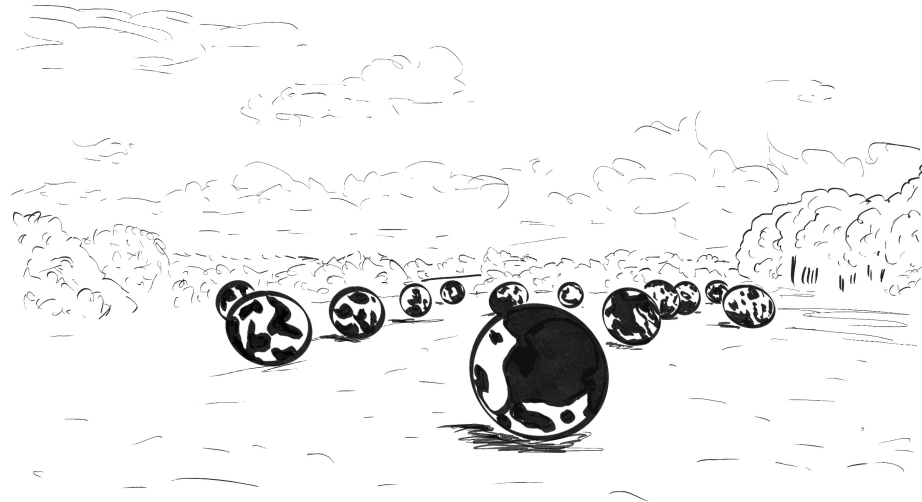
# Physicists are famous for studying cows...

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## ...but only if they are spheres





## Healthcare is often prone to simplification too

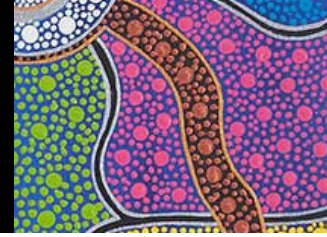
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“All patients are spheres!”

Not “biological spheres”

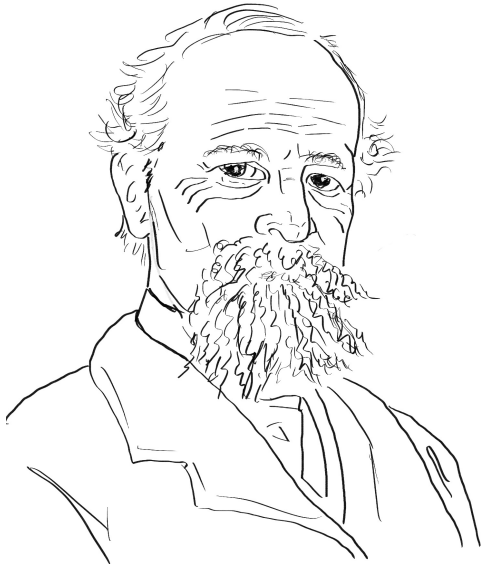
But “information spheres!”





## William James on Health Informatics

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“Ought it, indeed, to be assumed that the lives of all men should show identical religious [health information] elements? In other words, is the existence of so many religious [patient] types and sects and creeds regrettable?”

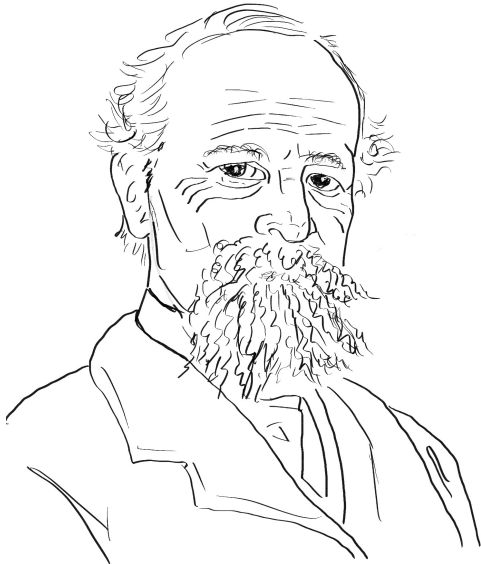
“To these questions I answer ‘No’ emphatically.”





## William James on Health Informatics

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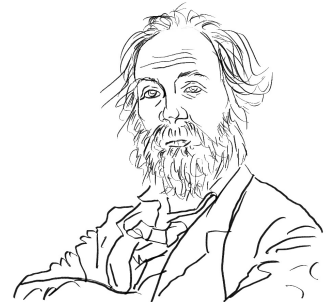
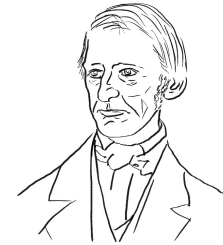


“And my reason is that I do not see how it is possible that creatures in such different positions and with such different powers as human individuals are, should have exactly the same functions and the same duties.”



## William James on Health Informatics

“If an Emerson were forced to be a Wesley, or a Moody forced to be a Whitman, the total human consciousness of the divine [healthcare] would suffer.”





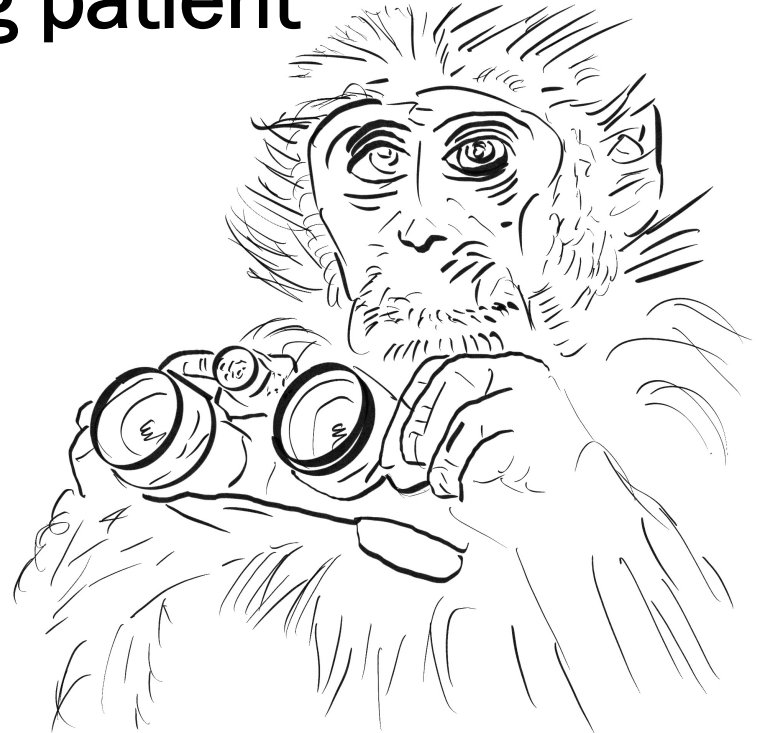
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Yet...



# Whether I'm a monitoring patient

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## Or a blunting patient





## Whether I'm happy to be on the sideline

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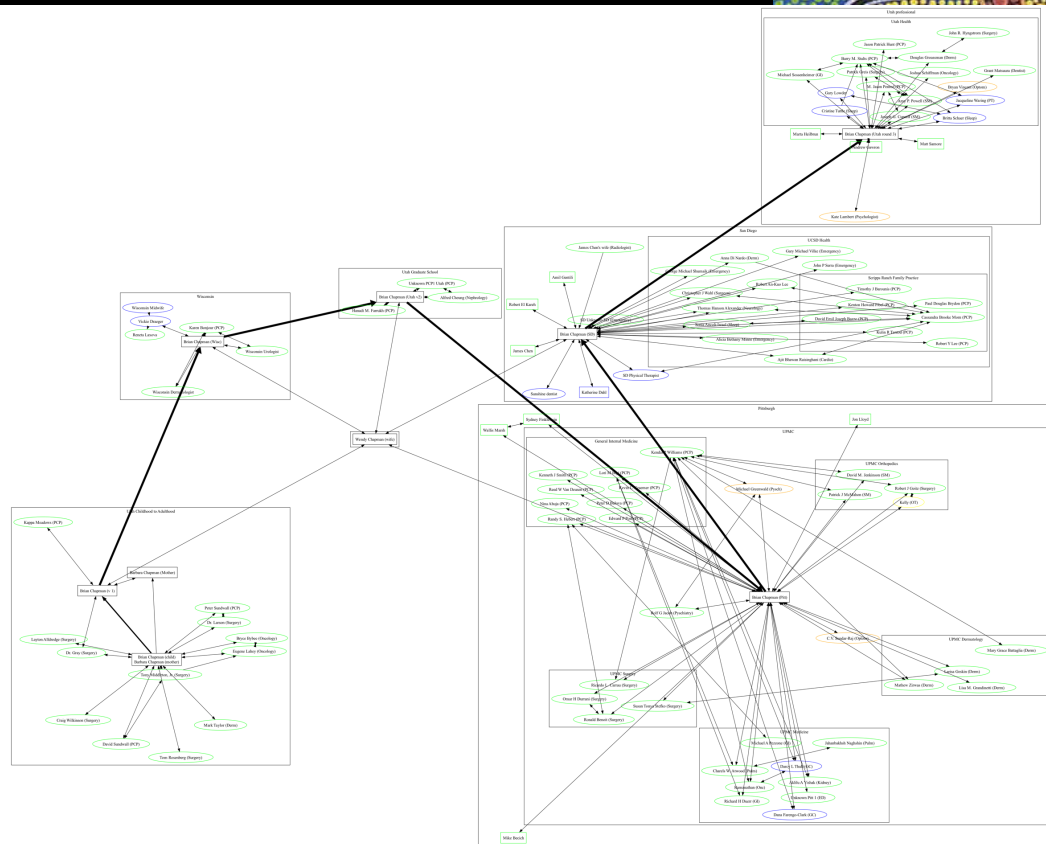
## Or I want to be in the middle of the team

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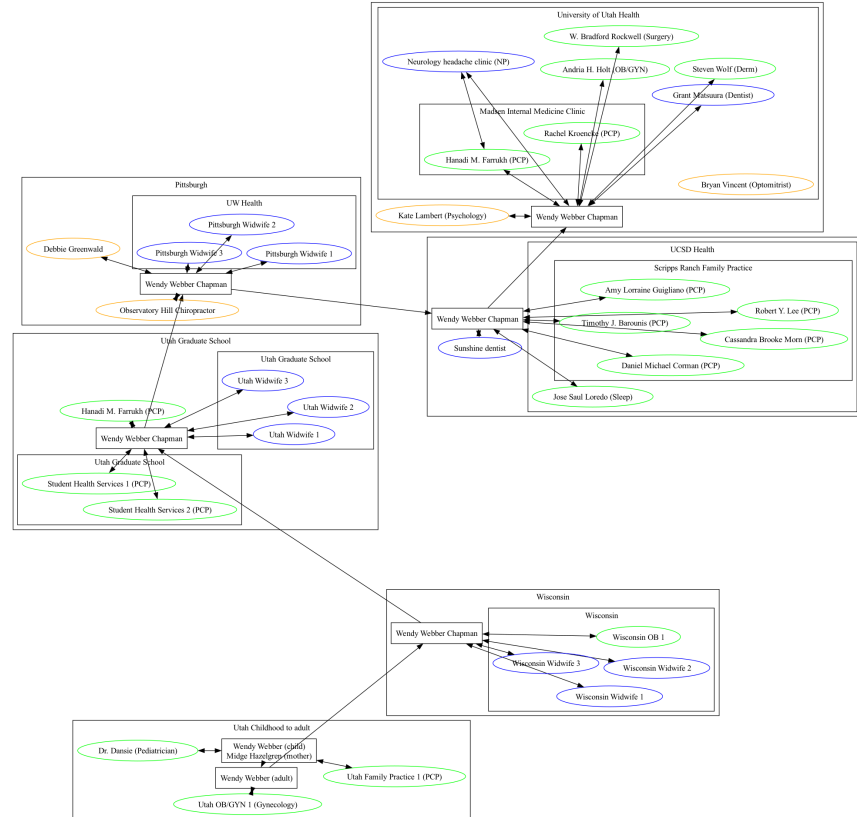




Whether my  
network of  
care is  
large...



## ...or small(er)





Patients are all given the same health information tools!



# Why?



## Jay Katz, M.D.'s 1980 diagnosis of medicine

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## Jay Katz, M.D.'s 1980 diagnosis of medicine

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1. Modern medicine adopted uncritically ancient medicine's dictum of not disclosing
  - Medicine had to hide its ignorance and ineffectiveness
2. Clinicians' transference of their own uncomfortableness with uncertainty to patients
3. Undervaluing patients as persons with values and capabilities
  - All patients are spheres!

Informatics largely inherited these same issues from medicine





## Epistemic pressures since 1980

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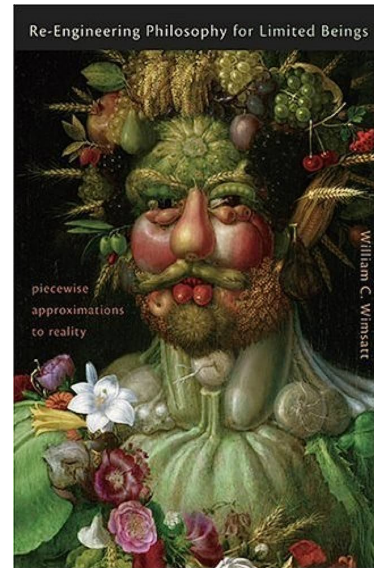
1. Medical errors
2. Expanding recognition of patient as person
  1. Values distinct from clinicians
  2. Capacities
  3. Epistemic rights



## Patients are valuable for metabolizing error

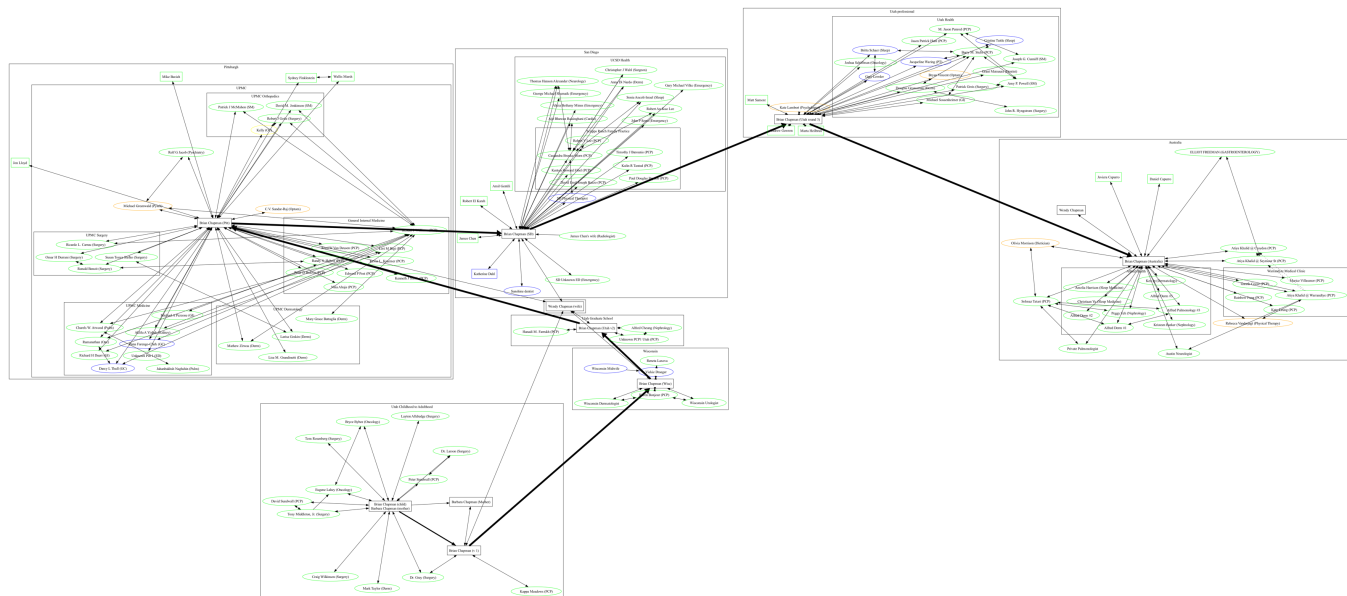
“We are *error-prone* and *error tolerant*—errors are unavoidable in the fabric of our lives...We learn more when things break down than when they work right. *Cognitively speaking, we metabolize mistakes!*”

(William C. Wimsatt, “Normative Idealizations versus the Metabolism of Error”)





# My

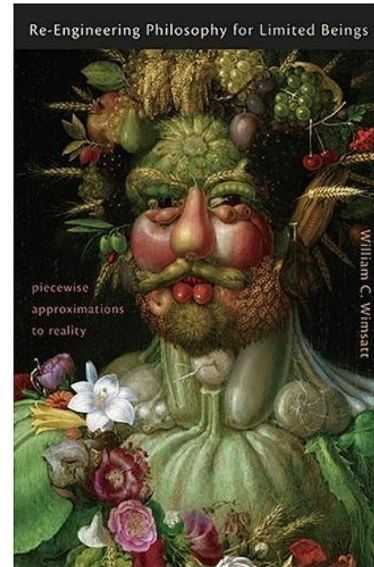




## Patients can be critical information redundancies

“Our adaptive mechanisms must be capable of detecting and responding to—nay, feeding on—errors at different levels and across varied contexts, and **exploiting parallelisms and redundancies.**”

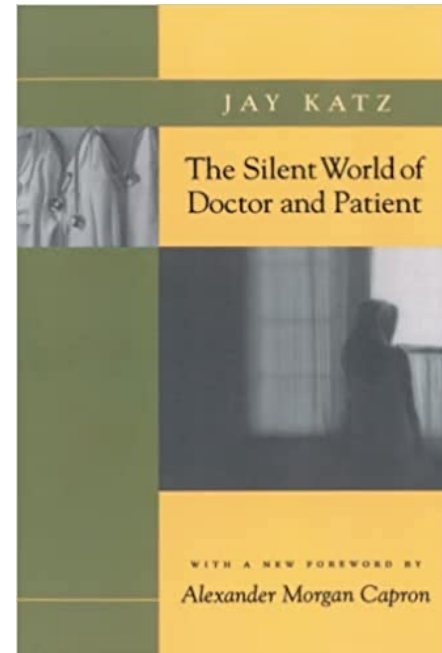
(William C. Wimsatt, “Normative Idealizations versus the Metabolism of Error”)





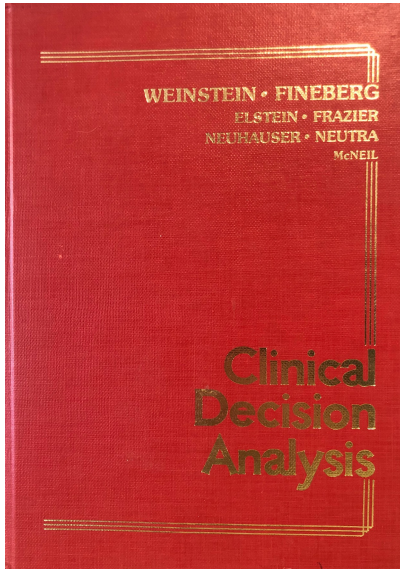
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“To recognize others fully requires not only an appreciation of their limitations but their capacities as well. Physicians have shown a keen sensitivity to patients' decision-making limitations but **considerable insensitivity to their capacities to decide.**”





## “Capacities to decide”: Freeman Dyson as patient







## “Capacities to decide”: Larry Weed, M.D.

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“We never give patients their records.”

“We do not have the time to give the medicines that way. It would not be safe to leave her with them unattended. She is on many powerful drugs.”

“The patient is not very well educated, and I do not think she could do all the things your questions imply.”



## “capacities to decide”: Larry Weed, M.D.

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“But,” I said, “you said she is going home this afternoon. She lives alone. At 2 pm you will put her in a wheelchair, give her a paper bag full of drugs, and send her out the door. Are you going home with her?”

“No. Is her management at home our problem?”

“You just said she could not handle it. Who will do it? The patient may not seem well educated or very bright to you, but **what could be more unintelligent than what you are doing?**”





## Universal needs of diverse patients

- Both the brilliant, well-educated Freeman Dyson and the “not very well educated” patient of Weed’s story—as widely different as they are—are autonomous agents that *must* act on their own.
- They have epistemic needs



## Epistemic rights

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- Rights to
  - Data, information, knowledge, understanding particularly related to our selves
- Epistemic injustices
  - Hermeneutical injustices (Impeding self understanding)
  - Testimonial injustices



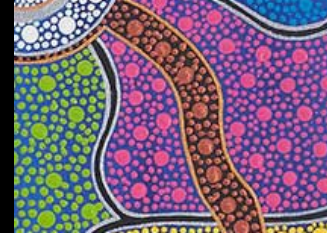
## Hermeneutical Injustice: How we get to know

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My Health Record

Other pathology reports are available to access 7 days after upload, allowing time for your healthcare provider to review and discuss the results with you. You will be able to see the report in your record but **won't be able to open the document during this 7-day period.**



## Hermeneutical Injustice: How we get to know

“Reading [medical diagnoses and prognoses] in the medical portal has been an empowering thing for me ... there was something that has been disempowering about having a doctor tell me.”

(<https://momastery.com/blog/we-can-do-hard-things-ep-215/>)



@andreagibson



## Testimonial Injustices: Ignoring Patient's data





## Testimonial Injustice: Ignoring patient's data

- "Not medical grade,"
- "Not reliable..."







## Patients *are* indeed Persons

- Person-patients are wildly variable
- Health systems commit epistemic injustices when they
  - Fail to provide patients with their data
  - Coerce patients into one-size-doesn't-fit all information eco systems
  - Do not provide mechanisms for patients to utilize their own data









# Way back in 1973

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The month I started kindergarten!

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## **SOUNDING BOARD**

### **GIVING THE PATIENT HIS MEDICAL RECORD: A PROPOSAL TO IMPROVE THE SYSTEM**

Predicted a proliferation of a health information services marketplace



## Have some imagination!

- Time to treat patients as 21<sup>st</sup> Century persons
- Eliminate monolithic solutions where patients are guests
- Replace them with a marketplace of solutions—a variety of “sects and creeds”—that patients can pick to match their incredible inherent variety

