

# “They Don’t Look Disabled to Me!”



Ethical Insights for Invisible Disabilities

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# “They Don’t Look Disabled to Me!”

Ethical Insights for Invisible Disabilities  
(or)

## Humbling Lessons for a Bioethicist About Stuff I *Thought* I Understood While Temporarily Able-Bodied

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## Invisible\* Disabilities

Chronic conditions that are rarely apparent to others, but that impede function and reduce quality of life

- \* ‘observed’ is not always *visual*
- You have to “live inside this body” to notice the problem

- Often experiential rather than functional
- Chronic fatigue
- Chronic pain
- Many mental illnesses, brain injuries

## “Somewhat Visible” Disabilities

Chronic conditions that limit opportunities and impair more of one’s life than the body systems or organs that others observe to be involved

- Incontinence
- COPD/asthma/heart disease
- Infertility
- Addictions
- Compromised immune system

## No Longer T-A-B: Fibromyalgia

- Chronic myofascial pain across whole body
  - Prone to injury, slow to heal
  - Abnormal pain response
- Chronic fatigue, non-restorative sleep
- Depression, anxiety, “fibro-fog”
- Prone to autoimmune, other comorbidities
- Causes?
  - Neurological/CNS
  - Rheumatic
  - Immune

## Common Themes (Stuff I thought I knew)

- Loss, Grief
  - Opportunities, activities, successes, people
- Power of Diagnosis, Naming
  - Not “real” until validated by an expert
  - “Sick role”
  - Access to help
- Self-identity reshaped
  - Roles, body image, hopes/fears
- Stigma
  - Fear of having same fate

## Invisible Themes (I had *NO* idea!)

- Loss, Grief
  - Opportunities, activities, successes, \$, people
  - Losses *denied by patient, others > overtaxing self worsens condition*
  - Sacrifices, losses perceived as chosen rather than consequences of condition
- Power of Diagnosis, Naming
  - Not "real" until validated by an expert; sick role
  - Accused of "faking it", being weak
  - Diagnosis may depend on whether a treatment is available, rather than accessing

## Invisible Themes (I had *NO* idea!)

- Self-identity reshaped
  - Roles, body image, hopes/fears
  - Body still looks "normal"
  - No role models // age, visible impairment
- Stigma
  - Perplexed, annoyed rather than fearful
  - Sympathy more common when
  - Brought on self: "poor coping"

## Injuring the Invisibly Disabled

- "It isn't that bad"
  - Can't know another's experience
    - It might actually be that bad today (or worse)
  - Reaction: defensive argument to persuade you it *is* that bad - wastes energy
- "Mind over matter"
  - Only works if the material body can respond to the mind
- Chirpiness

## Eleanor Stein MD, FRCP(C)Psych.

"Assessment and Treatment of Patients with ME/CFS: Clinical Guidelines for Psychiatrists" 2005

- "ME/CFS is *not* a psychiatric disorder"
  - Diagnosing co-morbid depression, anxiety vs. symptoms in ME/CSF
  - Treatment and Empowerment guidelines
- Burke clinic for the treatment of chronic pain and fatigue disorders  
2210 - 2nd St. SW Calgary, Alberta T2S 3C3  
● cdnpsych@telusplanet.net

## Stein on Empowerment

"From a psychotherapeutic perspective, one can observe a change in emotional status when the patient has the moment of realization that his/her opinions are as valid as anyone else's, that s/he is not to blame for his/her disorder and that s/he has value and rights despite being ill. From that point onwards patients cope better even if their physical condition or life circumstances do not improve."

## Phases of Coping: Patricia Fennell in Stein

- Phase 1: Crisis
- Phase 2: Stabilization
- Phase 3: Resolution
- Phase 4: Integration

All four phases raise ethical questions and insights that apply far beyond that phase, and even beyond disability



## Phase 1: Crisis

- Occurs whether onset is sudden or gradual. May recur in cycles.
- Develops when one's values, self concept, and life goals are called into question, i.e. you are too sick to function as you used to.
- The action goal is to batten down the hatches, take stock of resources, adjust expenditure and try to minimize immediate pain. A tool of phase one is to begin a personal narrative.
- The spiritual goal of phase one is to learn to allow one's suffering.

## Phase 1: Ethical Implications...

- Universality: we are temporarily able bodied at best
- Pain relief, therapeutic resources
- Practical assistance

## Phase 1: Ethical Implications

- "Allow one's suffering"
  - Validate other's experience w/o comparison, judgment, evaluation
  - Support need for self-care
  - Support withdrawing if necessary, but never abandon another in distress
  - Make room for suffering, vulnerability in language, pace, expectations, images
  - Confront own tendencies to denial

## Phase 2: Stabilization

- Occurs when one's physical condition has stabilized somewhat due to the lifestyle changes one has made.
- People in phase 2 continue to think they can function as they used to and continue to overestimate their personal resources. They have relapses as a result.
- The action goal is to focus on what one really needs. The tools of phase two are learning, restructuring and educating others.
- The spiritual goal of phase two is to learn to regard your suffering with compassion.

## Phase 2: Ethical Implications...

- Challenge expectations
  - How much *has to be done*, and what can be left undone?
  - Fair allocation of duties among (temporarily) stronger/healthier and those less so
  - Priority setting: where to invest available energy, concentration, etc
  - Redirecting: take advantage of strengths, talents instead of insisting on former / "normal" activities
  - Social, institutional norms: How do competition, lifestyle, pace, etc. cause / worsen disability?
    - Sue Wendell, *The Rejected Body*

## Phase 2: Ethical Implications...

- Education
  - Patient education about resources, therapies, coping strategies, self-assessment, etc
  - Educating others about existence, nature, range of invisible disabilities
  - Education of all about ways to help, hinder management
- Support for family, loved ones
  - Divorce common in chronic illness, pain

### Phase 2: Ethical Implications...

- “Regard suffering with compassion”
  - Observe “how much effort you have to spend to do what I do without thinking”
  - “It must really suck to go through this.”
  - “I’m sorry you’re struggling today”
  - “I’m here with you, even if I can’t fully understand what you’re going through”

### Phase 3: Resolution

- Grief work, the challenge to obtain insight and develop meaning in the face of huge losses.
- Patients are more self-reliant and self-trusting with regard to health decisions.
- Humor, play become possible again.
- The action goal is to stand for oneself without apology.
- The spiritual goal is to meet one’s suffering with respect.

### Phase 3: Ethical Implications...

- Grief support
  - “It sounds like your body has disappointed you”
  - “It just hit me how many things you’ve had to give up”
- Humor and Play
  - Support (do not demand)
  - >> Can laugh *and* cry
- Offer assistance, but don’t coddle

### Phase 3: Ethical Implications...

- “Patients are more self-reliant and trusting with regard to health decisions”
  - NOT justification for challenging competence, undermining informed consent & choice!

### Phase 3: Ethical Implications...

- “Stand up for oneself without apology”
  - Assumptions of control, responsibility for health status as well as productivity, reliability, etc.
  - Feeling apologetic for how you *ARE* is devastating
    - Alternative: “Look how well I’m doing with all that I’ve got to deal with!”
  - Are expectations unreasonable? (above)
    - Should apology come from those expecting, rather than those who “failed” to meet expectations?

### Phase 3: Ethical Implications...

- “Meet one’s suffering with respect”
  - ‘Respect’ means to embrace, accept the entire human person, not just the parts we like best
  - If we can meet *suffering* with respect, then we have hope of achieving genuine respect for each other, ourselves



### Phase 4: Integration

- Becoming more than one's illness frees up emotional energy for other meaningful tasks and interactions.
- One begins to connect the personal to the world view and embrace the mystery and unknown of life.
- The spiritual goal of phase four is to integrate your suffering into a whole life.

### Phase 4: Ethical Implications...

- A person never was "just" their illness or disability
  - We sometimes get lost in pain, concern, grief, frustration, exhaustion, etc.
  - Reminders of the whole self - and respect for the whole self - are necessary when person is overwhelmed by their body

### Phase 4: Ethical Implications...

"I'd rather be a human dissatisfied than a pig satisfied; I'd rather be Socrates dissatisfied than a fool satisfied. And if the pig or the fool think differently, it is because they only know their own side of the question."

John Stuart Mill

### Phase 4: Ethical Implications...

- Moral maturity:
  - Accept complexity of life, people
  - Accept limitations, inability to control
  - Integrate oneself into ethics
    - honest assessment of resources, etc
    - Carol Gilligan
- Integrate disability's lessons of compassion, humility, generosity, into one's outlook and interactions

### Final thoughts

A PhD doesn't mean you know anything important. Pay attention before you are forced to learn the hard way.

Celebrate every better-than-yesterday day.

*Thank you for allowing me to share this journey with you!*