Living on the Edge of Uncertainty

The Chronic Illness Experience: A Patient’s Perspective

Marina Symcox, PhD
GI ST Support International
Arthur Frank, PhD

“At the Will of the Body: Reflections on Illness”

“Because we can choose how we experience illness, we can be more than victims.”
My Story: rescue at death’s door.

“When you learn that your life is threatened, you can turn toward this knowledge or away from it.” (Anatole Broyard)

- Dx with terminal GIST at age 38 yrs. (1997)
- Internet support group as a life line.
- Recovery by imatinib. (Oct. 2000)
Observations about Serious Illness

―Being ill is a perpetual balance of faith and will.‖ (Arthur Frank)

Coping versus Personal Transition

- Adjustment is not an end point personality change.

- Continuous personal adaptations over time are required for ever changing circumstances.

―Disease‖ of the body versus ―Illness Experience‖ of living with broken body

- Disease can not be separated from a person’s identity.

- ―Disease treatment‖ is NOT ―Care of Illness.‖
Adaptation to Illness: Stoicism versus Dialogue

- **Stoicism:** an internal choice to detach from an external crisis.

- **Dialogue:** interactive social context to make sense of an external crisis.

“Storytelling seems to be a natural reaction to illness. People bleed stories, and I’ve become a blood bank of them. (Anatole Broyard)
Dialogue and Illness Narratives:

“The Wounded Story Teller” (Arthur Frank)

“The opportunity to tell one’s own illness story as one wants to tell it—in one’s “own” voice—is a kind of grace.” (Arthur Frank)

- **Restitution Stories**: medicine is hero, patient passive, health restored.
- **Chaos Stories**: trapped in unsurpassable adversity.
- **Quest Stories**: patient is hero, meaning, perseverance.

**Challenge for Support Groups**: Can you grant equal authority to all types of illness stories?
Mourning What is Lost

“You eke out your illness…only you will love it”

“All of my old trivial selves fell away, and I was reduced to essence.” (Anatole Broyard)

Mourning is an affirmation of the life that has been led.

Avoid those who seek to minimize what you have lost.

**Loss of:** freedom to plan, continuity with your past and your body, some relationships, connection to cultural mainstream, innocence about your mortality.

“Sinking all the way through, and discovering a life on the other side.” (Arthur Frank)
“I would like a doctor who is not only a talented physician, but a bit of a metaphysician too. Someone who can treat body and soul…I just wish he would brood on my situation for perhaps five minutes” (Anatole Broyard)

“Life threatening illness gave doctors a new dimension of importance for me. I had never expected so much from them or been so sensitive to their shortcomings.” (Arthur Frank)
Experiences in the Health Care System

- Non-recognition of the Illness Experience: Medicine is disease management oriented. Patient Angst, demoralization.

- Asymmetry of medical intimacy: patient feels vulnerable, passive.

- Falling through the cracks of bureaucracy, many handlers = anonymity, lack of continuity.

- “Medicalization” of the Illness Experience: Is tragedy a disease requiring an anti-depressant medication?
Cancer in (American) Popular Culture

“Healthy people comfortably accept the social myth that illness behavior is inside the person.

We want to enclose the ill person in a psychological language that turns his reality inward, closing it off to external influence.

Then we hand the whole thing over to medicine.” (Arthur Frank)
Cancer in (American) Popular Culture

- The Cancer Personality. (repackaged as “stress and your immune system”)

- The Tyranny of Positive Thinking. (Jimmie Holland)
  Comforters who are Accusers. (AF)

- Myth: Cancer brings enlightenment, or closer relationships.

- Myth: Metaphors that Stigmatize. War Analogies.

- Myth: Glossy media images of cancer patients.

- The Cost of Appearances (AF). Denial benefits whom?
Living with Terminal Disease

“Some prevail by continuing to live; some prevail by dying. Those who are ill and those who witness illness can only have faith in the wholeness of either outcome.” (Arthur Frank)

- Search for meaning and spiritualism.

- Faith to accept whatever happens and at the same time a will to bring about change.

- Redefinition of personal scale (time and space). Changing family dynamics.
“Wellness and sickness perpetually alternate as foreground and background…

In health there can only be fear of illness, and in illness there is only discontent at not being healthy.

In recovery I see not health but a word that has no opposite...Gravy.” (Arthur Frank)
The Remission Society & Valuing Illness

Finding Gravy:

- “The sick person’s best medicine is desire—desire to do things, to get back to his life.” (AB)

- Celebration of recovery, wonder, and losing it if recovery goes too far.

- Redefinitions. “If freedom requires good health, then it is precarious indeed.” (AF)
The Remission Society & Valuing Illness
Finding Gravy:

- Illness as a dangerous opportunity for personal growth. (hazards of becoming an illness narcissist)

- Forfeiting my disease as my drama, and watching it flourish as “Somebody else’s Intellectual Property of Research.”

- Relishing half opportunities, finding generosity of spirit.
Marina’s Favorite Books (in English):

- Arthur Frank, PhD  *At the Will of the Body: Reflections on Illness.*

- Anatole Broyard  *Intoxicated by my Illness and Other Writings on Life and Death.*

- Jimmie Holland, MD  *The Human Side of Cancer: Living with Hope, Coping with Uncertainty.*
Books

- Gilda Radner  It’s Always Something.
- Zoe Koplowitz  The Winning Spirit:  Life Lessons Learned in Last Place.
- Sherwin B. Nuland, MD  How We Die:  Reflections on Life’s Final Chapter.
- Viktor E. Frankl, MD  Man’s Search for Meaning.