

Lecture Outline: Health Activism & Patient Rights Movements

Section 1: The Disabled Activist

Introduction: Definitions

- 1. Historical Context of Patient Rights**
- 2. Issues: Redefining Disability**
- 3. Issues: Disabling Practices**
- 4. Issues: Independent Living**
- 5. Issues: Mainstream Cultural Attitudes**

Section 2: The Activist Cancer Patient

Introduction: Culture & cancer

- 1. Patient Activism & Community**
 - 2. Issues: Visibility**
 - 3. Issues: Research Agendas**
 - 4. Issues: Treatment**
 - 5. Issues: Fundraising**
- Conclusion: Common Threads**

Activist patient challenges medical establishment & cultural mainstream:

- how his/her situation is defined**
- nature of medical practice & treatment**
- how their illness is dealt with in everyday life**
- activist patients often labeled 'bad patients'**

For disabled people, activism is focused around redefining disability, not in biomedical terms as sickness, but as people who have to live in a society that disables them.

Cancer activists are critical of biomedical interpretations of their disease, critical of treatment & research, critical of the closeted 'hidden' nature of disease, and critical of fund-raising tactics.

Historical Context of Patient Rights

- **disability groups from 1890s in Britain & USA**
- **1970s inspiration from Civil Rights Movement, polio & Thalidomide survivors**
- **1981 United Nations International Year for Disabled People**

Issues: Redefining Disability

- **discarding medical model**
- **impairment as universal**
- **Redefining disability**

Issues: Disabling Practices

- **social
marginalization**
- **disabled people
bring private
'imperfect' body
into the public
world**

An impairment is the loss of some physiological or anatomical function, impairment is relatively verifiable in 'objective' terms. - But a disability is the consequence of such an impairment, i.e. the inability to climb up stairs independently, for example.

“Independent Living is about the whole of life and it encompasses everything. We want equal opportunities. We want citizenship. It is philosophical, it is political, it is about integration and disabled people becoming part of this world and not separate, segregated and second class.”

John Evans, 1993

Issues: Independent Living

- **1973 Centre for Independent Living, University of Berkeley**
- **1979 English Grove Road Scheme**
- **Camphill Communities**

Camphill Communities Ontario will create social environments that enhance spiritual expression and quality of life with individuals of diverse abilities.

Camphill Communities Ontario contributes to society by creating opportunities for people of all abilities to fulfill their potential through living, learning, and working in community.

Issues: Mainstream Cultural Attitudes

- disabled people - healthy or sick or something else?
- shifting line between 'normal' & 'disabled'
- Halpern - sympathy vs empathy & the failure of imagination

Illness as Metaphor by Susan Sontag

- cancer - symbol of death
- cancer - the invading alien
- cancer - a secret stigma

Breast Cancer

- **global rates of breast cancer doubled 1980-2000**
- **highest rates: USA, Canada, Britain & Europe - Chinese women lowest rates**
- **breast cancer most 'hidden' cancer**

Breast Cancer Activism & Community

- Breast cancer organizations early 1990s – links to women's movement and AIDS activism
- 1993 Canadian National Forum on Breast Cancer, Montreal
- Grassroots Activism, i.e. Toronto's Willow Breast Cancer Support & Resource Services

Breast Cancer Activism & Community

Visibility

"We continue to feel that others are doing things to us rather than for us. When I decided to speak out publicly, I felt exhilarated...engaged in a personal, meaningful struggle."

Sharon Batt, Cancer Activist

Issues: Visibility

- **Femininity & the cancer patient**
- **looking 'normal' & the 'good' patient**

Issues: Research Agendas

- research agendas
- funding prevention research
- environmental factors
- the economies of treatment vs prevention

Issues: Treatment

- **Dr Susan Love – critical of chemotherapy**
- **CAM therapies**
- **% of alternative therapy cancer patients small but growing - younger, higher socio-economic groups**

GREENS: Dark leafy greens like collards & kale are rich in cancer-preventing carotenes, chlorophyll, anti-toxidants, folic acid & flavonoids. Greens are excellent complementary medicine for those choosing radiation therapy.

Issues: Fundraising

C.I.B.C. Run for the Cure

Toronto, 2004

- **Marketing the fight against breast cancer?**
- **Informal alliance of cancer charities, large corporations, the state & media**