Patient Advocacy Organizations and the Pharmaceutical Industry

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GOALS OF THE PROJECT

- **Explore** the variety of relationships between patient/advocacy groups and the industry
- **Identify** best practices
- **Produce** recommendations
- **Insure** transparency and independence
THE FIRST PROJECT ASSIGNMENT: The Typology of Patient/Advocacy Groups

What are patient/advocacy groups?

What is their mandate?
National Voluntary Health Organizations

Mission:
To control/prevent a particular disease with community involvement.

- National Association for the Study and Prevention of Tuberculosis (1904)
- American Cancer Society (1913)
- American Heart Association (1915)
- National Foundation for Infantile Paralysis (1938)
NATIONAL VOLUNTARY HEALTH ORGANIZATIONS (continued)

- **Founders**: scientists and physicians who exercised leadership

- **Boards of Directors**: philanthropists devoting personal wealth

- **Women volunteers**: raising money and consciousness on a local level
Expanding the Patient/Advocacy Mission: 1945-1970

Scientific Research as Social Capital

Leaders -
- Mary Lasker (American Cancer Society)
- Eleanor Roosevelt

Goal -
- Expand the resources of the NIH to combat common diseases: cancer, cardiac disease, mental health

- Informal organizations
- Small budgets
- Founders were survivors of targeted disease counselors

Reach for Recovery

- Founded by breast cancer survivors
- Activity: To help women cope with the physical, emotional, and social toll of mastectomies
The first time a group with a prior political identity targets a disease.


Strategies:
- Political action - attack the FDA, sit-ins
- Challenge scientists - attack RCTs
- Do not attack pharmaceutical companies
- Encourage the development of therapies
- Promote lay people as experts: drug trial registries
Diffusing the AIDS Model

- Patient advocacy groups focus on specific diseases (breast cancer as opposed to cancer).

- Hypothesis: this is the point of entry for pharmaceutical company funding.

- Focus on a particular group that includes both survivors and those defined at high risk.
Breast Cancer Patient/Advocacy Organizations: The Personal is Political

- All women are vulnerable.
- 1 in 9 will contract it.

Breast cancer patient/advocacy groups:
- **Represent** the particular interest of their founders
- **Promote research**, both private and government, aimed at a cure
- **Accept donations** from corporations who want to be identified with their cause
- **Publicize** new drugs and devices
- **Publicize Clinical Trials** sponsored by government and industry
Brand search for a cure with races and walks

Trademark: logo

"Unfortunately, there's no cure—there's not even a race for a cure."
Diffusing the AIDS Model: Psychiatry

- Every DSM IV Diagnoses its own patient/advocacy group(s).

- Many of these groups form a close alliance with a pharmaceutical company that has developed a drug that treats behavior/symptoms.

- CHADD - Children and Adults with Attention Deficit/Hyperactivity Disorder (ADHD):
  - Advocate for services (schools, teaching assistants, summer camps)
  - Support biological rather than behavioral explanations
  - Promote pharmaceutical agents
  - Provide psychological support for parents
  - Self-conscious efforts to reduce stigma
  - Extensive lobbying efforts for research dollars and services
Diffusing the AIDS Model: Genetics

- Each disease has its own advocacy group
  - Hereditary breast cancer (BRCA mutations)
  - Gaucher’s Disease
  - Tay Sachs Disease
  - Huntington’s Disease
- Founded by patients, parents (carriers), potential patients (genetic susceptibility)
- Direct interest in the outcome
- Promote research
- Encourage donation of tissue and blood samples for research
- Close relationships with researchers and pharmaceutical companies
Chart the complex relationships between patient/advocacy groups and the pharmaceutical industry.
Pharmaceutical companies court patient/advocacy groups

Donations come from marketing and sales departments

Goals:
- allies against restrictive formulary decisions
- allies adept at political action
- organizing protests
- testifying at hearings
Pharmaceutical companies sometimes create patient/advocacy groups

(Some/Many) patient/advocacy groups (both new groups and well-established ones):

- Accept company donations
- Promote company products
- Inform members of benefits (but perhaps not the risks) of the drugs/devices
RECAP: GOALS OF THE PROJECT

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