SOCIAL WORK and CYSTIC FIBROSIS

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Hmm, How to Sum Up Social Work

- Social work is a professional and academic discipline committed to the pursuit of social welfare and social change. The field works towards research and practice to improve the quality of life and to the development of the potential of each individual, group and community of a society (Wikipedia, 2010).

- Social work is “concerned with the interactions between people and their social environment which affect the ability of people to accomplish their life tasks, alleviate distress, and realize their aspirations and values” (Pincus and Minahan, 1973).

- Social Work practice consists of the professional application of social work values and guiding principles.
NASW Code of Ethics

- Ethical Responsibilities to Clients
- To Colleagues
- In Practice Settings
- As Professionals
- To the Social Work Profession
- To the Broader Society
SOCIAL WORK ROOTS

- Development of social work in US: Reflects an ongoing synthesis of ideas derived from many different cultures

- Goals: Included increasing access to suitable housing and medical care, obtaining fair wages, and providing health and life-skills education to the community

- Additional areas: Childbirth, alcohol and narcotic abuse, social equality

- Social work and health care: shared common goals and objectives from the beginning

- References:
  - http://www.mghpcs.org/socialservice/History.asp
  - http://www.ssw.umich.edu/ongoing/fall2001/briefhistory.html
ABBREVIATED & PARTIAL TIMELINE OF SOCIAL WORK IN THE US

- **Early 19th Century**
  Roots of US social work date back to this period; “friendly visitors”

- **Civil War (1861-1865)**
  Large-scale private social welfare initiatives (Red Cross)

- **1877**
  1st American Charity Organization Society (COS); Buffalo

- **1886**
  1st US settlement house established; NYC

- **Early 1900's**
  Social Wk Movement created many programs & services

- **World War I (1914-1918)**
  Expansion of government agencies; increased professionalism in departments devoted to social welfare

- **Depression (1930s)**
  Greatly influenced social work practice
  Redefined role of government as an instrument of social welfare

- **New Deal (1933-1936)**
  Policy changes that profoundly influenced social work profession

- **1955**
  National Association of Social Workers established

- **1960s**
  War on Poverty; Medicaid and Medicare
Medical Social Work Beginnings

- 1905: Dr. Richard Cabot, a senior physician at Mass General, hired the first social worker to provide social work services in the outpatient clinics.

- 1906: Dr. Cabot hired Ida M. Cannon to jointly organize the nation's first hospital-based social work program.
  

- 1914: Cannon was named Chief of the Mass General Social Service Department, the first organized social work department in a hospital.

- 1918: Founding of the American Association of Hospital Social Workers.

- 1938: SWs 1st began to include social summaries in medical records.

- Beginning during World War II and growing thereafter were weekly conferences between social workers and physicians and nurses.

References:
http://www.harwardsquarelibrary.org/unitarians/cannon_ida.html
http://www.mghpcs.org/socialservice/History.asp
To provide compassionate and efficient services to all persons seeking treatment by:

- Empowering our patient's to their highest level of social, mental and physical well-being.
- Encouraging our patients to do as much for themselves that they are able.
- Focusing on prevention, treatment and education.
- To use our specialized knowledge of the interactions between personal, biological and psychological elements with the socioeconomic forces of the environment.
- To be innovative and creative in our solutions to problems.
- To be dedicated to respecting and valuing racial, cultural and individual differences.
- To provide excellence in customer service.
Introduction to Social Work and CF

Cystic Fibrosis is a complex chronic illness that has tremendous impact on patients and families at many levels including physically, financially, emotionally, psychologically and spiritually. The CF social worker serves as a member of the CF team to assist in the care of the patient and family.
What do we mean by “Chronic Illness?”

- Chronic illness is ongoing; entire life; no cure
- Examples: heart disease, diabetes, cancer, CF
- Statistics:
  - In 2005, 133 million Americans – almost 1 out of every 2 adults – had at least one chronic illness.
  - About one-fourth of people with chronic conditions have one or more daily activity limitations
  - Chronic diseases account for 70% of all deaths in the U.S., which is 1.7 million each year.
  - Arthritis is the most common cause of disability, with nearly 19 million Americans reporting activity limitations

Reference:
http://www.cdc.gov/chronicdisease/overview/index.htm
How do social workers provide care in CF?

Family Centered Care
The Beginnings of Family Centered Care

- In the early 1980’s, care for children with disabilities and special health care needs began to shift from a diagnosis-specific approach to a whole child approach.
- Individuals with Disabilities Education Act (IDEA) promotes greater control/decision making authority
- End of that decade, the shift had moved to a philosophy of family centered care. (team planning meetings)
What is Family Centered Care?

Family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care provider, patients, and families. It redefines the relationships between and among consumers and health providers.

Family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of individuals and families and restore dignity and control to them.

Family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.
Cornerstones of Family Centered Care

- Informational Sharing

- Collaboration between patients, families, and health care staff
Social Work Research

- There is not a lot of evidence based guidelines for social work and CF specifically
- NACFC (North American Cystic Fibrosis Conference)
  - Poster Presentations
  - SWs looking to encourage more SW to do research to back practice with patients
- CF-SOCIAL-WORKERS@LISTSERV.DARTMOUTH.EDU
  Forum for CF Social Workers around the country
Social Work Role with CF Patients/Families

- Psychosocial assessment
- Emotional support
- Counseling and psychiatry referrals
- Insurance and patient assistance program information
- Advocacy for patients and liaison
- Financial resources and housing
- Employment
- Education College Scholarships
- Support for parents and caregivers
- Transition issues from child to adult
- Reproduction issues
- Lung transplants
- End of life issues
- Liaison with other agencies
- Collaborate with the team
Psychosocial Assessments

- Process of acquiring relevant information needed to develop a plan for working with patients/families; encompasses environment, support system, values, beliefs, economics, resources, interests, family, housing, education, cultural, spiritual
- An ongoing process, not a onetime assessment
- Each interaction– meet the pt/family where they are; what are their needs today?
Emotional Support – Slide 1

- Grief and loss
- Living with the unknown
- Feeling alone
- Uncertainty about progression of disease
- Complex treatment regimens

“How much we ask of patients for the treatment regimen, and what they must do to try to be healthy”
Emotional Support – Slide 2

- Regular clinic visits, hospitalizations
- Financial stress due to costs of care
- Disruptions in future plans
- Anxiety and depression
- Impact on Relationships
Referrals

- Psychotherapy/Counseling
  - Insurance issues
- Psychiatry
“Wow! You need professional help.”
Insurance

Access to insurance = better access to medications, treatments, health care

- Type of insurance
  - Private - how to keep it, plans vary
  - Medicaid
  - Medicare

- Medications
  - Co-pay Programs, Uninsured programs
Advocacy

- Systems
  Examples: School, Mental Health, Primary Care, Utility Companies, CF Team, Insurance, Employer

- Laws
  Examples: Family Medical Leave Act, 504 Plans/IEPs, Health Care Reform, Americans with Disabilities Act
Resources

- Financial
  SSI/SSDI, Dept of Economic Security, emergency assistance
- Employment
  Vocational Rehabilitation, Jobs with Insurance, Short-Term and Long-Term Disability, Accommodations
- Education
  GED classes, JobCorps, AmeriCorps, CF Scholarships, Early Head Start, Head Start
- Legal
  Southern Arizona Legal Aid, CF Legal Hotline, Catholic Services
Support for Parents and Caregivers

- Child care
- Social networking
- Child development
- Parenting teens
- Sibling relationships
Transition

- What Is Transition?
The passage from one state, stage, or place to another
- What are the Stages of Transition?
Different for different ages
- Impacts of CF on Transition
  Delay in puberty
  Ahead of peers/behind peers on an emotional level
  Intimate relationships
  Peer relationships (e.g., Do peers know about CF?)
- Support systems
- Dependence on caregivers
- Parental/caregiver involvement
- Parental/caregiver thoughts/feelings re: CF
- Experiences with medical team/hospital
- Treatment regimen during development
- Career

Lecture on Transition: 10.18.11
Reproduction

Person with CF
Able to have biological children?
Males want to be tested?
Whether to have children?
How to have children?
How to talk to partner?

Parent of child with CF
Whether to have more children?
How to have more children?
Genetic testing?
How to talk to child about reproduction?
Lung Transplants

- Talk to patients about lung transplants
- Issues: timing, age, team members, process
- Referral to transplant team
- Psychosocial workup
- Advocacy re: transplant
- Denial
- Insurance issues
- Private insurance, AHCCCS
- Other facilities around the country

Lecture: 4.3.12
End of Life Issues

- Home care
- Advanced directives
- Hospice
- Bereavement

Lecture: 11.29.11
Challenges

- What we are up against with CF
  - foreshortened lifespan
  - isolating illness
  - treatments are very time-consuming and expensive
- Myriad of issues faced by patients/families and time constraints
- Very limited resources/historical times
Possible Solutions

- Listening to patient/family
  - not one-size fits all
  - being real with what is; looking at patient/family as a whole
  - building trust
  - social networking
- Talking to patient/family between clinic appointments and in the hospital
- Persistence; developing relationships