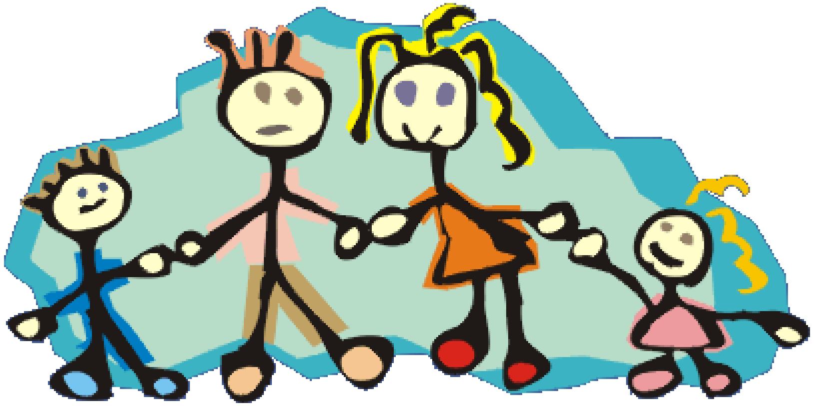
Family Strategies for Living with Rare & Chronic Illness



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3 “SOURCES” FOR TODAY’S DISCUSSION

- 20 years of clinical work with pediatric pts & families
  - (15 in peds neph)
- Dissertation study with pts and families with cystinosis
- Presenting “strategies” back to families and teens with cystinosis and other diagnoses
  - FSGS, aHUS

- What are the strategies developed by families for living with illness?
  - SW ethics and values – strengths perspective, culture competence, respect for persons, self-determination
- What defines “success”? What defines “family”?
- Why focus on families rather than individuals (or “patients”?)

CYSTINOSIS IN EMERGING ADULTHOOD
STUDY PARTICIPANTS

Focus groups and individual interviews with:

48 individuals from 21 families

- Individuals with cystinosis (age 18+)
  - 12 women, age 18-39
  - 10 men, age 18-47
- Family members:
  - 13 mothers
  - 11 fathers
  - 2 sisters
  - 2 husbands
  - (two small children and a dog)

TYPOLOGY AND TIMEFRAME OF ILLNESS

- Unexpected and unexplained, part of family health history, lifestyle choices
- Genetic, environmental, infectious?
- Rare or common
- Progressive, “stacking up”, or Stable
- Debilitating (functional loss, slowly or quickly)
- Episodic, constant, or relapsing
- Chronic or acute
- Visible or invisible
- Fatal and/or life-threatening, life-changing

(Rolland, J. (1994). *Families, illness, and disability:*
An integrative treatment model. New York: Basic Books.)

"DISEASE" AND "ILLNESS"

"*Disease* refers to a malfunctioning of biological and/or psychological processes, while the term *illness* refers to the psychosocial experience and meaning of perceived disease".

Kleinman, A. (1981). *Patients and Healers in the Context of Culture*

- Your daily life
- How you perceive yourself/your loved one
- How others perceive your experience
- What language do we use to talk about this experience???
  - Coping, quality of life, "living with illness"

HOW HAS ILLNESS CHANGED THINGS?

What's happening in family's life while illness is "happening"? (diagnosis or long haul)

Age of person diagnosed?

Relationship(s) and role(s) - parents/spouse/kids

School or work status?

Outlook on life? Adversity? What's valued?

HOW ILLNESS AFFECTS FAMILIES

Unexpected/frightening illness experience(s)

The diagnostic “journey” or “event”, and “the long haul”

Grief at loss of normalcy

Family member in a “sick role”

Scheduling and planning around illness

Treatment(s) not cure

Having hope vs. despair

Treatment and monitoring ongoing (no rest!)

STRATEGIES OF SUCCESSFUL FAMILIES

FROM PATIENTS AND FAMILIES REFLECTING BACK ON CHILDHOOD AND ADOLESCENCE

Educating

Regimenting

Protecting and Pushing

Connecting

Finding a Fit

How can we listen for and support these strategies?

EDUCATING

Coming to Understand

What is it like hearing medical information?

Whoa!

“Overwhelming”

- Give/get info in small doses, practice “teach back”

Individuals and families gain control as they educate themselves, share with one another, and are able to communicate with providers (and researchers) effectively

Pts/fams come to understand medical language and complex biologic and genetic processes!

Let’s recognize their accomplishment and expertise!

WOW!

WHAT FAMILIES CAN DO

Learn as much as you possibly can and share with your family and friends…and school…and medical team… and illness community.

Ask questions. Encourage your child/your family to ask. Even if questions are hard to ask, or seem “simple”.

Write down questions and take notes when getting answers. Practice asking those questions beforehand.

There isn’t an answer? **Keeping asking.**
Why isn’t there an answer? What’s needed?

- Energizes advocacy & new research questions

- **What HCP’s can do – connect families/pts to resources!**

USING WHAT YOU KNOW

Don't lie/apologize/bribe for treatments/procedures

Find age-appropriate ways to explain to a child

- (SW or Child Life can help)

Simple, straight-forward info leads to

- preparation and acceptance

Well-meaning people may still say the wrong things

- (including HCPs, school, friends & relatives & neighbors)
- Use those teachable moments!

Knowledge helps you advocate –

- school and work
- know the laws, too

> Always very simply, based on his understanding. We told him that it was a disease that made his kidney sick, tried to do it a simple way… It's always something we talked about from the age he could talk.

EDUCATING THEMSELVES AND THEIR CHILDREN

REGIMENTING

Organizing life to manage illness

Happens over time, returns sense of control

The "logistics" of adherence?

Adapt your normal routine (or create a new one)

- Be deliberate!
- What's in your backpack/purse/wallet/pillbox?
- Map daily/weekly/monthly schedule
- Predictable symptoms or side effects?
- What and who are your resources?

- Apps, calendars, alarms
- Care binder, USB drive, Medic-alert, "passport"

Creating habits

- Some things aren't negotiable, some things are
- *Becoming acclimated*

> Taking my pills was like brushing my teeth. It was just an everyday thing that I had to do.

> I have to stop what I'm doing and take medicine. I know it's for the good… growing up with it was normal for me. It was something that I did. It's just part of me.

REGIMENTING AND BEING ACCLIMATED

A FAMILY'S (AND PATIENT'S) BALANCING ACT:

<<<<< Push >>>>>

Don't drop standards

Set high expectations
- School/Work/ Community
- Go easy on incentives

Participate at home

Encourage empathy

Identify strengths
- find new areas to excel

Adapt

> "If she wanted to do something, well, okay, we'll figure out a way to do it."

>>>>Protect <<<<

Recognize limits

Learn to say no

Be flexible

Educate others

Advocate
- for things that promote health and success

Accommodate

Have you all seen "I am Sam?"

CONNECTING

The power of the social network

Many forums

In person and on-line – meetups, lunch & learn, etc

Others share your experience

- comparing notes/buffering

See successes, setbacks, what lies ahead

- Witnessing/scaling

Being/going public

- What to disclose to who/when/where
- Becoming a mentor or advocate

- WHERE AND HOW DO PATIENTS CONNECT IN YOUR PRACTICE?

COMING TO TERMS & FINDING A FIT

- Integrating illness into family life or centering family life around illness symptoms and treatment.
- There is no single answer

- Acceptance/"new normal"?
- Recognizing good days and bad days
- Every family and individual will (re)negotiate how they live with illness over time.

LIVING IN/VALUING THE NOW

- Recognizing the reprieve
- Mindfulness
- Gratitude

Maximize the moment!