

SPIRIT ROLE-PLAY: NONCOMPLIANCE

TASK: To work out appropriate medication for Lia Lee. At this time, Lia is about 3 years old. She has had eleven hospitalizations for seizure disorder, sometimes accompanied by fever, pneumonia, and infections of the middle ear. She has also had several episodes of status epilepticus. Both her doctors and her parents are very concerned. Her regimen should be some combination of Tegretol, Dilantin, and Phenobarbital; Tylenol and Valium for fever; ampicillin if has an infection; also antihistamines, bronchodilators. Some of the medication are in pill form, many either white or red, some are elixirs. The Lees have to be instructed to break some of the pills in half; some pills have to be pulverized and given with food; some are given daily, some, as needed etc. Basically what should be communicated is a fairly complicated drug regimen. Also, some of these medications require regular blood draws to monitor levels.

Caveat: There are no “bad guys” in this role-play. Everyone is trying to do his or her best

NAO KAO –

View of epilepsy – dangerous, but also a sign of distinction; a healer’s disease
Thinks American doctors don’t understand about the soul, and illnesses caused by soul loss
Doctors are an intrusion; doctors hurt Lia
Upset that last time Lia was in the hospital, she was tied to the crib, yet in his absence had somehow fallen out and bumped her head; thought hospital care was sadistic; at another hospitalization, Lia had to be intubated, which was distressing
Feelings – suspicion, resentment
Western medicine makes Lia sick
Thinks too much medication causes seizures and fever
Believes child is parents’ responsibility, not doctors
Values independence and autonomy – doesn’t like to be told what to do
Spent \$1000 on healing herbs for Lia from Thailand
Has sacrificed chickens and pigs for Lia; is considering sacrificing a cow (this is very expensive and a really big deal)
Wants to take Lia to Michigan to see a famous txiv neeb
Can’t read either English or Hmong
Sometimes tells doctors they’ve run out of medication, and haven’t refilled prescription, because this seems like an excuse doctors can accept; sometimes says they are giving the medications to Lia even when they aren’t because doctors seem to like to hear this
Thinks Neil is a good doctor who wants to take good care of Lia
Is willing to compromise with “a little medicine and a little neeb” (spiritual healing)

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NEIL ERNST

View of epilepsy: a neurological disorder

“My job is to practice good medicine; the parents’ job is to comply”

Priorities are controlling epilepsy, preventing retardation and neurological damage in the patient

Concern is that noncompliance with medication endangers Lia

Feelings – frustration, anger, helplessness; out of control, rage; fear

Very afraid of “the big one” (huge status epilepticus seizure); has nightmares about this

“I want to shake the parents so they’ll understand”; feels like he’s banging his head against a wall

Wants parents to administer medication properly; doesn’t want a double standard of care

Wants parents to pay attention to Lia’s temperature

Needs to know that medications are given accurately, so can adjust levels appropriately

Feels Nao Kao puts up a stone wall; sometimes he is deliberately deceitful; Foua is either “very stupid or a loonybird”

Wants to show the Hmong community that certain things are not acceptable: “I feel it’s important for these Hmong to understand that there are certain elements of medicine that we understand better than they do and that there are certain rules they have to follow with their kids’ lives. I want the word to get out to the Hmong community that if they deviate from that, it’s not acceptable behavior.”

Is prepared to involve Child Protective Services to remove Lia from the home if parents won’t cooperate

Upset parents missed Lia’s last appointment

Thinks Jeannine Hilt is a “pain in the ass”

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FOUA –

View of epilepsy – accepting of the epilepsy: not everything is in our control

Priorities – loving Lia; making sure Lia is not unhappy; purifying Lia’s spirit

Feelings – unhappy that Lia is unhappy

Likes medications that can be delivered once, preferably by injection; shouldn’t have to take a medication forever

Doesn’t like to give Lia phenobarbital because causes diarrhea

Doesn’t like to give Dilantin because changes Lia’s spirit and makes her face look different; she becomes wild

Doesn’t like to give Lia medications she doesn’t like

Doesn’t like that doctors keep taking Lia’s blood – she only has so much

Like Nao Kao, can’t read labels; doesn’t recognize numbers; can’t read a thermometer

Missed last appointment because couldn’t find Lia’s Medi-Cal card

Changes dosages of medications because thinks medications are too strong; sometimes doubles dosage if medication seems to be helping

Stops medications entirely when Lia seems well

Foua likes Jeannine – sees her as Lia’s benefactor, because gives the disability money

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LIA –

Walks around, periodically hugs and kisses people; mostly clings to mom

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EFFIE BUNCH (visiting nurse composite) –

Lia is really spoiled

Has tried many plans, all have failed; feels burned-out

Has tried everything – colored stickers, moons and suns for night and morning; drawing lines on the medicine droppers; charts; taping pills to a calendar; putting pills in pill boxes

Upset because mother changes dosage of medications

“Sometimes I think the whole family should be placed in a psychiatric hospital”

the Hmong are set in their ways, rigid, stubborn, backward “You cannot get through to them”

Parents are sullen, uncooperative, always say yes when they have no intention of doing what you want

POTENTIAL RESOURCES

JEANINE HILT (social worker/psychologist composite) – loves Lia; understands that Lia is very special to the parents, like a royal person; might grow up to be a shaman; she asked the Lees what they thought caused Lia's illness

Determined to educate Lees about Lia's medications

Willing to spend dozens of hours with Foua

In favor of radically simplifying medical regimen

Thinks Nao Kao has reason to be upset with medical system

Truth is not as important as consensual reality

Understands anti-authoritarian stance of Hmong

Thinks Lees are smart, communicative and energetic

Has been to Lee's home many times

Is aware of money spent on amulets and animal sacrifices

Made effort to translate medication instructions into Lao, not realizing no one in family can read

ARTHUR KLEINMAN (psychiatrist; medical anthropologist composite)

Would suggest questions such as:

- 1) What do you call the problem?
- 2) What do you think has caused the problem?
- 3) What do you think the sickness does? How does it work?
- 4) What kind of treatment do you think the patient should receive?
- 5) What is the most important thing you hope will result from this treatment?
- 6) What are the main problems this sickness has caused?
- 7) What are you most afraid of about this illness?

Might suggest creating a performance of traditional Hmong characters in which the evil dab doesn't want Lia to have medication, but the powerful healers and good spirits think some medicine will help Lia keep her soul; include drumming, chanting, dancing, incense

BRUCE THOWPAOU BLIATOUT (Hmong medical administrator; elder composite) – can mediate

Can act as cultural broker – make suggestions such as talking primarily to husband, and don't undercut his authority; wishing the family good things; try to avoid being patronizing, threatening, or critical; don't blame, and don't try to make Lees feel guilty for Lia's deterioration; enlist support of community leaders and members of Lee clan; reassure about limiting blood draws; be open to conjoint treatment – welcome shamanic or homeopathic practices that you think won't do harm and might help

DISCUSSION QUESTIONS * SPIRIT

We'll be discussing the doctor-patient relationship, focusing on communication issues, and one particular ethical dilemma raised in the book. Please be thinking about a learning issue that you'd like to pursue and we'll be listing these in the last 10 minutes of our session.

Patient-Doctor Relationship

How would you describe the patient-doctor relationship in Spirit?
What goes wrong in the relationship between the Lees (Foua and Nao Kao) and the Drs. Philp (Peggy and Neil)?

Lack of communication - literal and figurative
Differing expectations and understandings
Power struggle - teach a lesson

What are some of the physician feelings?

Frustration, anger, fear, helplessness; rage
Sorrow, lack of control
Neil - Nao Kao put up a stone wall; was deliberately deceitful
Peggy - Foua was either very stupid or a loonybird
Defects of either intelligence or moral character
Dan Murphy - awe at how differently they looked at the world
High-velocity transcortical lead therapy (shoot 'em)

What are some of the family's feelings?

Doctors an intrusion; doctors hurt Lia; doctors don't take good care of Lia; medicines make her sick
Suspicion, resentment, dislike
Complaints from Hmong patients generally pg. 62

What were physician priorities?

Controlling epilepsy; preventing retardation and neurological damage in patient

What were parent priorities?

Loving Lia; making sure Lia was not unhappy; purifying her spirit

Communication Issues

Lack of common language

Lack of adequate interpretation

Lack of common conceptual health belief reference points (no understanding of internal organs)

How did Hmong regard epilepsy?; how did this differ from biomedical diagnosis?
shouldn't have to take a medicine forever; epilepsy is dangerous, but also disease of distinction (healer's disease)
crisis the treatment, not the epilepsy; much more accepting, not everything is in our control

Ethical issues

How to address noncompliance

How to address child "neglect," "endangerment"

Professionalism

How would you define professionalism in this doctor-patient relationship?

DISCUSSION QUESTIONS * SPIRIT

In the Introduction to Humanities session, we'll briefly discuss the doctor-patient interaction, focusing on relationship and communication issues. Please think about the questions below.

Patient-Doctor Relationship

How would you describe the patient (parent)-doctor relationship in Spirit?

What goes wrong in the relationship between the Lees (Foua and Nao Kao) and the Drs. Philp (Peggy and Neil)?

What are some of the physicians' feelings?

What are some of the family's feelings?

What were some of the complaints about American medicine from Hmong patients in general?

What are the physicians' priorities?

What are the parents' priorities?

Communication Issues

What are some of the communication problems that occur between the doctors and the Lees?

What are some of the differing health beliefs of the Hmong and the doctors, especially in regard to the meaning of epilepsy; the role of medication; and the attitude toward disease in general?

Ethical issues

What are some of the ethical issues raised in the book?

Professionalism

What would you say about the extent to which professionalism is present or absent in this patient (parent)-doctor relationship?