

Brookhaven Hospital Tulsa, Oklahoma

Programs

- Behavioral Health
- Chemical Dependency
- Eating Disorders
- Neurological Rehabilitation Institute

Autonomy, Capacity and Beneficence: Ethical Considerations In a Disabled Population

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Disclosure Statement

My only disclosure is that I am an employee of Brookhaven Hospital in Tulsa, Oklahoma. The content of this presentation is designed to promote quality improvements in healthcare and not advocate for any particular provider or entity. In addition, every effort has been made for the information to be well balanced, evidence based and unbiased.

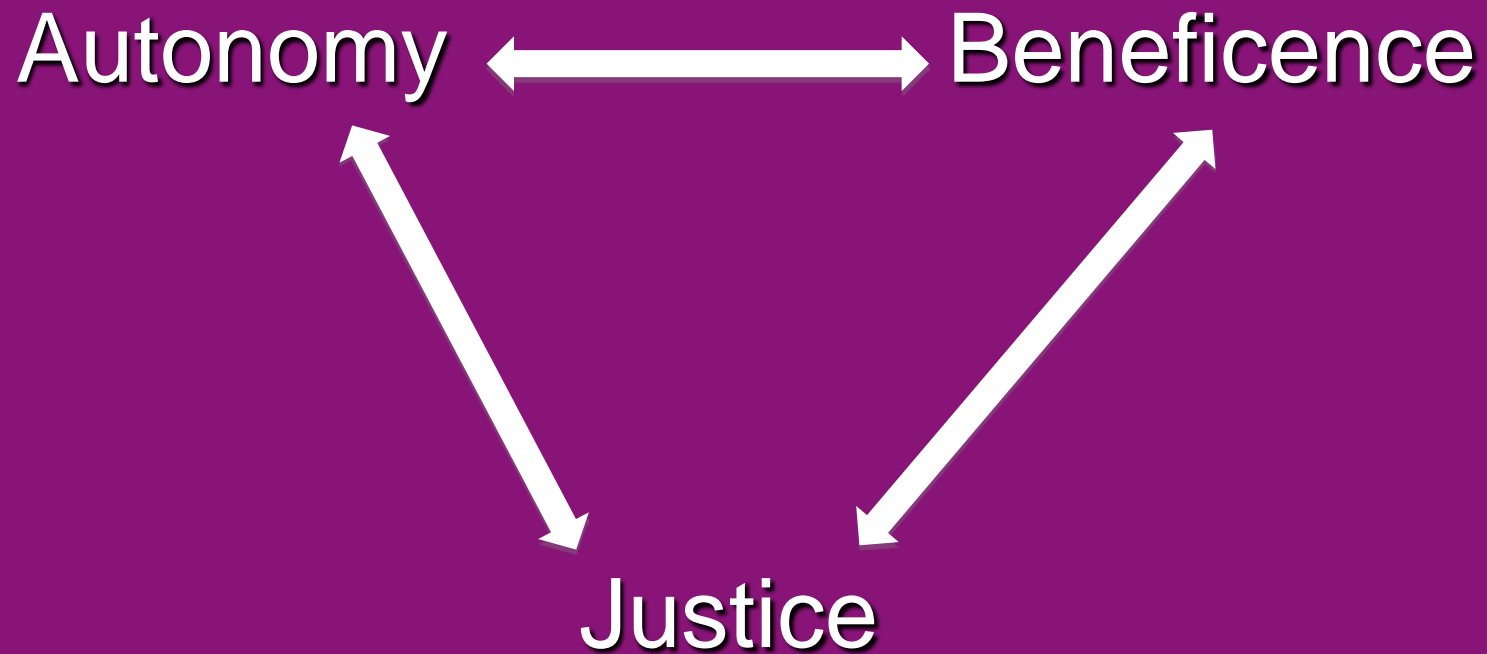
Goals

1. Understand pros/cons of autonomy
2. Know scenarios & ethical guidelines of capacity assessment
3. Question and weigh ethical benefits of treatment decisions
4. Know how to review treatment decisions from an ethical perspective
5. Challenge our thinking processes





Bio Ethics



How are we doing?

Brain Injury

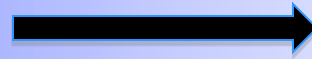
Treatment Since 1970

The 1970's

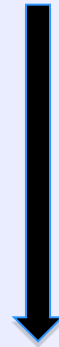


The Early 1980's

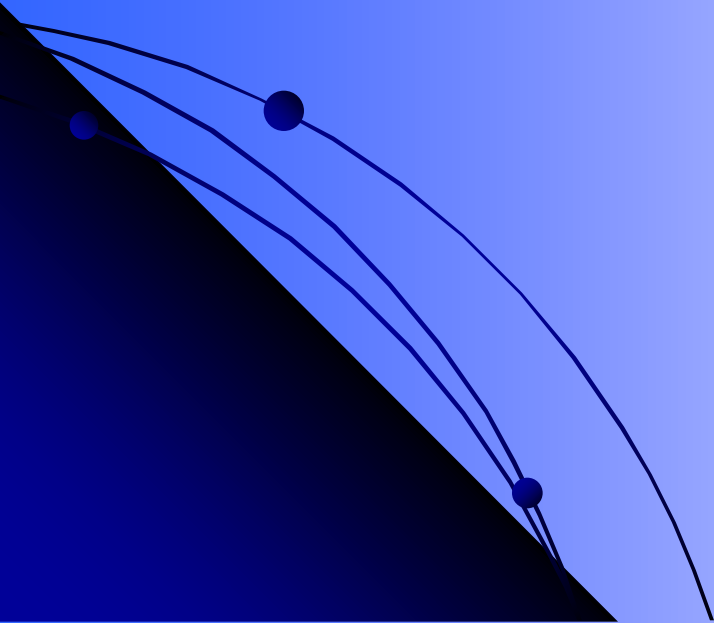
Brain Injury Rehab
Becomes Sub Specialty



Centers Grow
From 10 to 500+

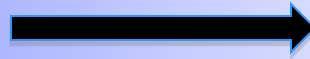


“Era of Proliferation”



The Early 1980's

Dr. Mitch Rosenthal &
The National Head
Injury Foundation



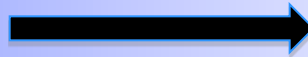
Becomes the
BIAA



Provide Support,
Education, & Advocacy
for Access & Funding

The Early 1980's

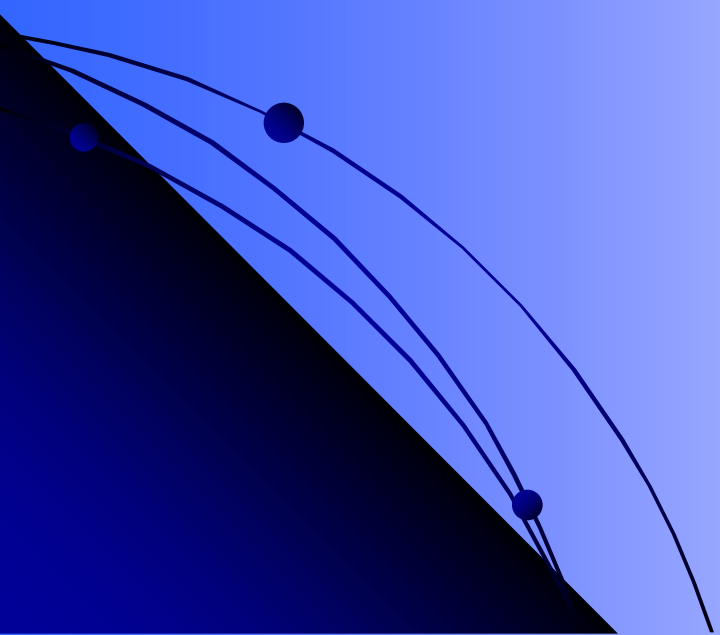
American Congress
Of
Rehabilitation Medicine



Dr. Sheldon
Berrol
Head Injury
Special Interest
Group



Advance Standards of
Care, Uniform Definitions,
Education & Training



The Early 1980's

Becomes



“The Consumer Era”

1986-1989

Public Questions

The Theory Base?

Interventions?

Efficacy?



1986-1989

The Response

CARF & Standards of Care

National Institute on
Disability Research

5 Model Systems of Care



1986-1989



Becomes

“The Era of Refinement”

The 1990's

Proliferation of Facilities

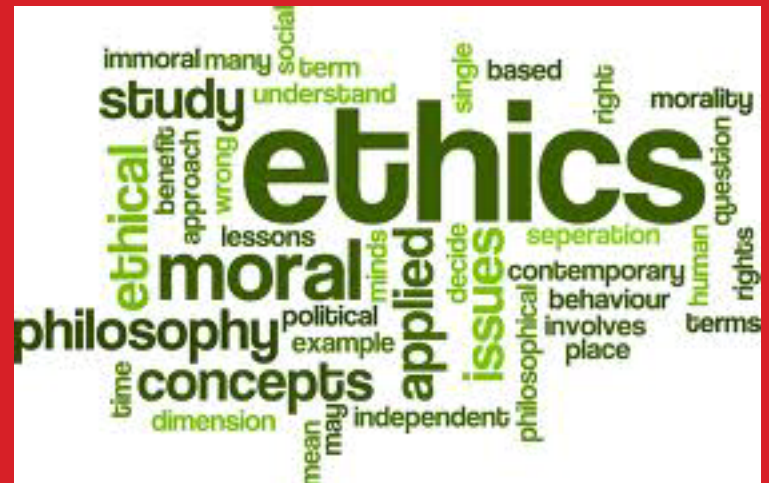
10-500+

The 1990's

Few Treatment Guidelines

The 1990's

Minimal Ethical Standards



The 1990's



Abuse

Scrutiny



The 1990's

National Head Injury Foundation
Develops Basic Guidelines for

Ethical Practice



The 1990's

“The Era of Accountability”



The 21st Century

Where Has the Evolution in Brain
Injury Rehabilitation Lead Us?

The “Era of Consolidation”

The Factors

Healthcare Reform

Insurance
Company Mergers

HMO's

Decreased LOS



Who Are the Stakeholders?

Insurance
Companies

Taxpayers

Consumer

Treating Professional

Families

What Are Their Questions?

Is the Treatment
Efficient?

Is the
Treatment
Efficacious?

Is the
Treatment
and Service
Satisfactory?



Treatment Efficacy

Time To Revisit Some 1996 Treatment Myths

Proposed by Dr. Mitch Rosenthal

Treatment Efficacy

Myth # 1

Treatment should continue for years?

Treatment Efficacy

Myth # 2

Most expensive
produces the best outcomes?

Treatment Efficacy

Myth # 3

Most interventions
are grounded in research?

Treatment Efficacy

Myth # 4

Need to be delivered
by high-skilled professionals?

Treatment Efficacy

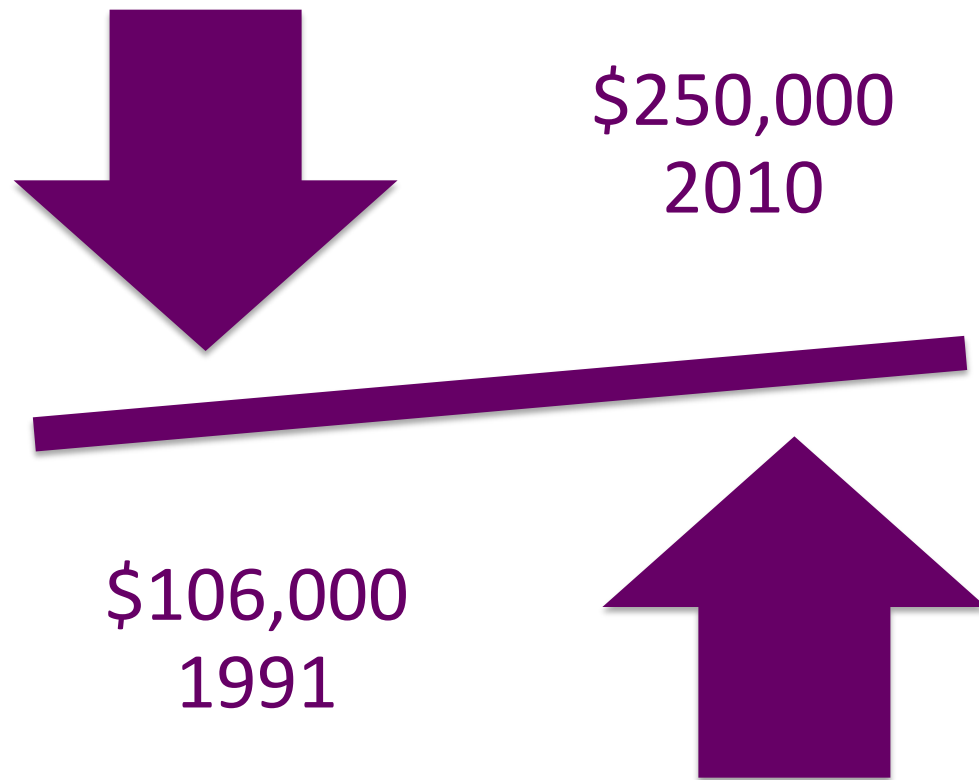
Myth # 5

Sub-acute delivers equivalent outcomes, as comprehensive rehabilitation?



A Short Look at One Reality

Johnson & Lewis 1991





Treatment did
not generate a
return to work.



“May be no more
effective than
support care.”



The Challenge

Banja states, “To the extent that a delivery system becomes an end in itself and loses sight of the needs of those persons it is intended to serve, that service delivery system runs a danger of creating a false need or advocating treatment or therapies simply because they are available, irrespective of whether the patient actually needs them.”



What Are We *Really* Doing?

Some Questions to Ask Ourselves

How do we ensure autonomy
during treatment?

What Are We *Really* Doing?

Some Questions to Ask Ourselves

Do we assess capacity
throughout treatment?

What Are We *Really* Doing?

Some Questions to Ask Ourselves

What evidence is there that our
treatment **benefits the consumer?**

What Are We *Really* Doing?

Some Questions to Ask Ourselves

Do we examine ethical issues
related to treatment decisions?

What Are We *Really* Doing?

Some Questions to Ask Ourselves

During treatment are we attune to
the ultimate outcome?

What Are We *Really* Doing?

Some Questions to Ask Ourselves

How do we view or ensure
consumer satisfaction?

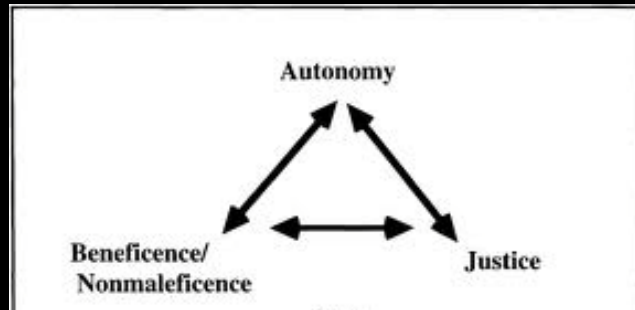
What Are We *Really* Doing?

Some Questions to Ask Ourselves

How are we holding ourselves
accountable?

Autonomy & Ethics

Principlism: The Foundation of Biomedical & Behavioral Research



The quality or state of being **self-governing**;
self-directing freedom.





Autonomy & Ethics

U.S. Supreme Court, “No right is held more sacred, or is more carefully guarded, by common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference from others, unless by clear and unquestionable authority of law.”



Autonomy & Ethics



John Stewart Mill

The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant.

Autonomy & Ethics

My
autonomy is
critical
to what you
do!



Autonomy and Ethics

Example

- Consumer enrolled in services
- We encourage participation
- Assume consumer will benefit
- Assume they don't know what's best
- Consumer refuses intervention
- We interpret refusal as evidence of need for treatment



Beneficence

- Doing or producing good
- Macciocchi's definition "the promotion of health as defined in part by the patient's own values."
- Basic tenets of principlism-a system of ethics
 - Autonomy →free-will or agency
 - Beneficence→to do good
 - Nonmaleficence →not to harm, and
 - Justice →social distribution of benefits & burdens

Beneficence



Doing good or producing good

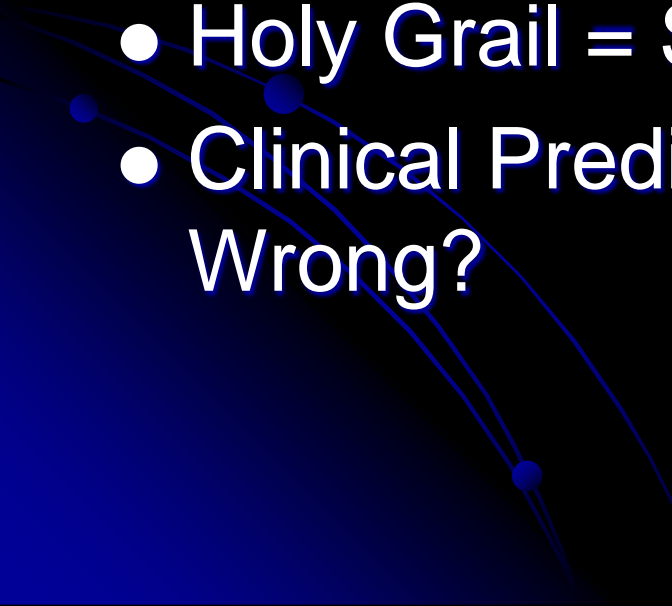
Beneficence



The promotion of health as
defined in part by the patient's
own values.



Pitfalls of Beneficence

- Beneficence vs. Respect for Autonomy
 - Beneficence Assumed vs. Compliance
 - Autonomous Person vs. Autonomous Choice
 - Holy Grail = Safety
 - Clinical Predictions: What If They are Wrong?
- 

More Challenges

1. Are we allowing consumer to express autonomy?
2. Is our treatment based in best practices?
3. If not, are we offering best-practices alternatives?
4. Are we blaming the consumer?
5. Is our assumption i.e., they need treatment, self-serving?
6. What about our value judgments?
7. How do we determine who knows best?

Capacity

Defined as the faculty or potential for treating, experiencing or appreciating.

1. Informed consent
2. Situational vs. Psychometric
3. Provider assumptions from observations
4. Fluid as rehab progress

Capacity

Person should demonstrate ability to understand:

1. Nature of condition warranting treatment.
2. Nature of proposed treatment.
3. Likely risk/benefit of proposed treatment.
4. Available alternative treatment including no treatment and risks/benefits.
5. Necessity that a decision has to be made.

Example 1

John: six weeks post TBI and possibly needs surgery. Doctor and wife talk while John is listening and without involving John, they agree to the surgery. Three months later John appears improved and elects to stop his medication. Doctor agrees.

Autonomy, capacity and beneficence addressed.

Example 2

Tommy, who is not his own guardian, is on post-acute unit and has attended cognitive group for three months. He decides he no longer needs to attend. Staff attempt to persuade him to no avail. Staff implement a plan where he loses points needed to attend the community outing.

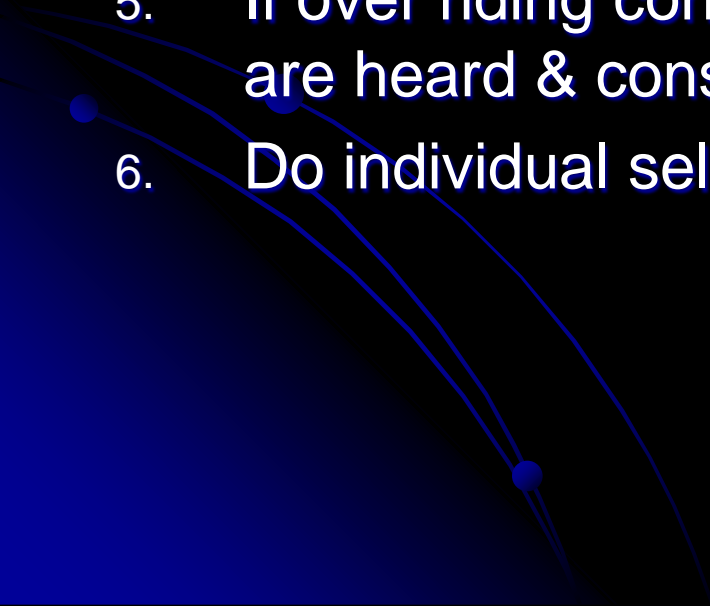
Autonomy, capacity and beneficence in question.

Tommy and Ethical Considerations

Questions

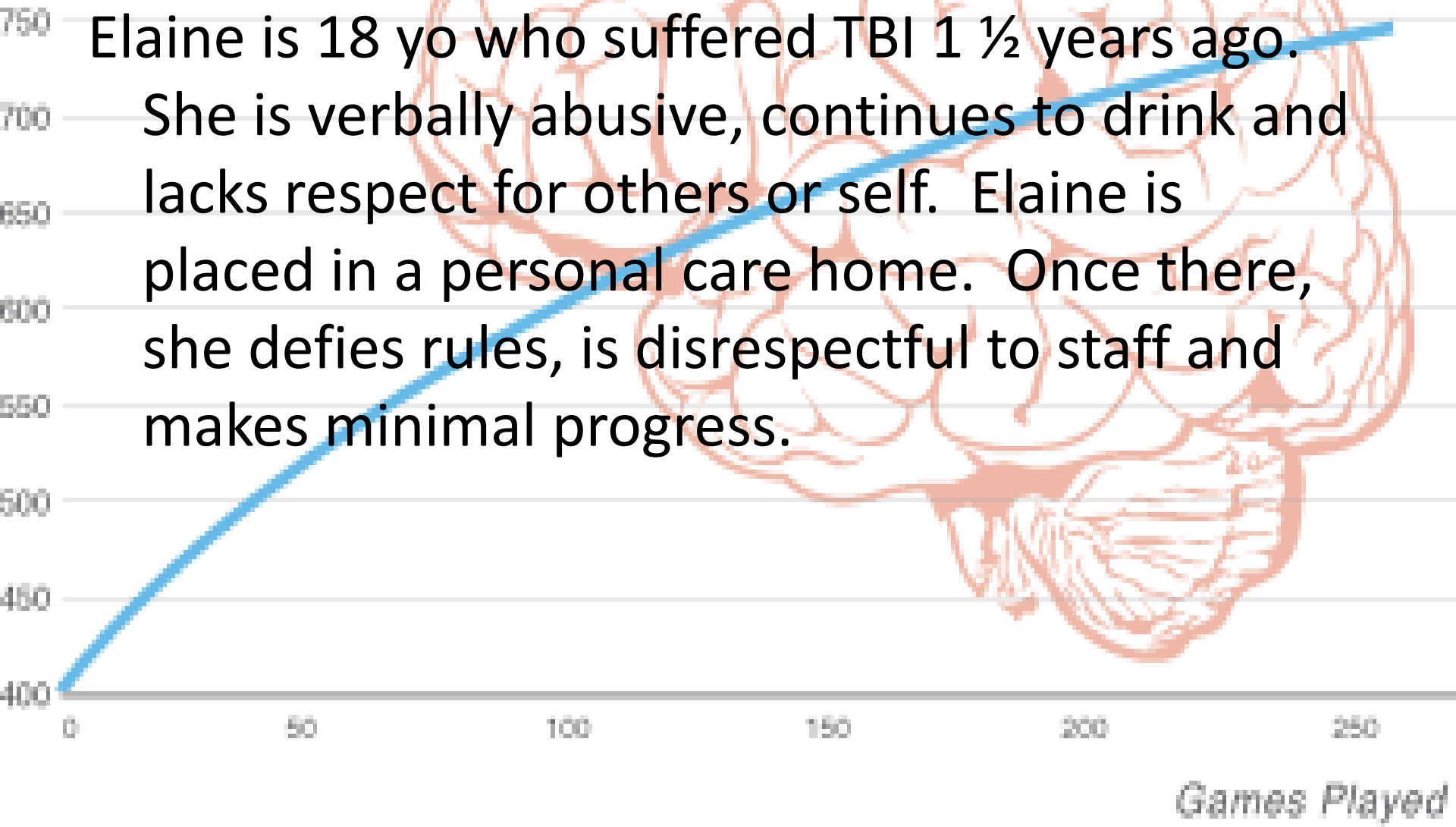
1. Is it ethical to generate consequences?
2. Is there a universal code of ethics?
3. Who ensures ethical practice in treatment?
4. Is there a need for ethical rounds?
5. What would ethical rounds look like?

Ethical Rounds

1. Complete a functional analysis including safety and risk.
 2. Consider the consumer's autonomy and capacity.
 3. Evaluate the pros & cons of possible decisions.
 4. Assist consumer with reconsideration of decision.
 5. If overriding consumer, ensure all team view points are heard & consider alternatives.
 6. Do individual self-reflection for bias.
- 

Example 3

Elaine is 18 yo who suffered TBI 1 ½ years ago. She is verbally abusive, continues to drink and lacks respect for others or self. Elaine is placed in a personal care home. Once there, she defies rules, is disrespectful to staff and makes minimal progress.



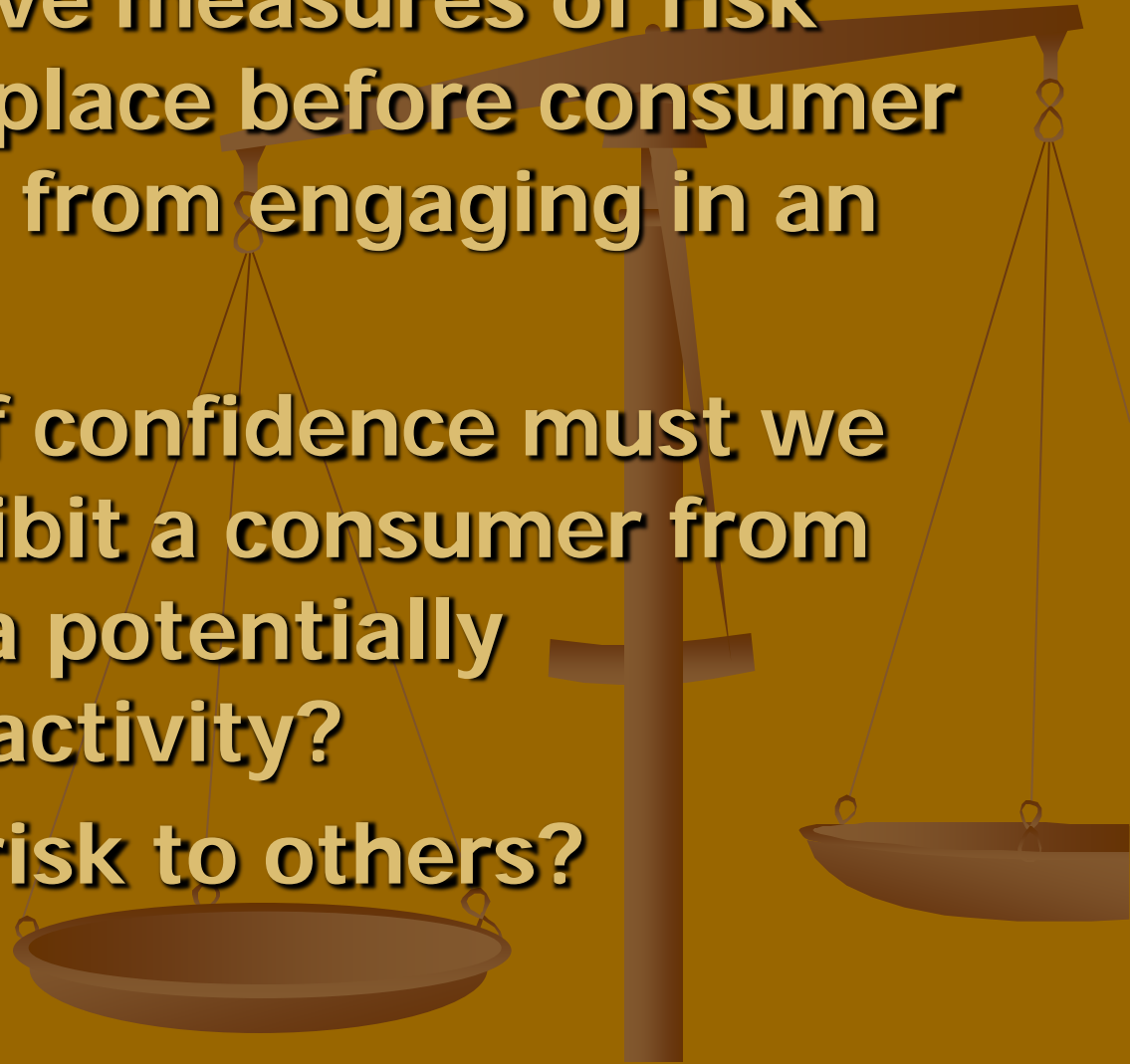
Autonomy, Beneficence & Disruptive Behavior

1. How do we grant autonomy with disruptive behavior?
2. Is it reasonable to think in terms of capacity?
3. How do we strive for beneficence?
4. Is it clinically or morally acceptable to discharge her?
5. Should she be forced into another program although likely it will be unsuccessful?



Risk Assessment

1. What objective measures of risk should be in place before consumer is disallowed from engaging in an activity?
2. What level of confidence must we have to prohibit a consumer from engaging in a potentially problematic activity?
3. What about risk to others?



Tepper & Elwork Model

- 1. Establish parameters of consumer's processing ability.**
- 2. Evaluate capacity to understand information related to decisions.**
- 3. Evaluate capacity to arrive at and communicate a treatment decision.**
- 4. Identify barriers to effective decision making.**
- 5. Remove the barriers.**
- 6. Evaluate effectiveness of interventions to improve abilities.**
- 7. Create longitudinal record of consumer's competency status.**

Family Involvement

Positive Aspects of Family Involvement

- 1. Support treatment team.**
- 2. Assist with transition skills.**
- 3. Represent consumer when needed.**
- 4. Speak to their hope & expectations of outcomes.**



Juvenal (2 A.D.)

Family & Conflicts of Interest

Who will guard the guardians?

1. When there is emotional turmoil?
2. Lack of sufficient information?
3. Resentment of incompetent consumer?
4. Weak or non-existent bond?
5. Conflicting financial interests?
6. Inability to separate interests e.g., financial and emotional burden or moral differences?
7. Professional's conflict of interests?

A Few Thoughts About Research, Evidence Based and Ethics

Research

The New Paradigm

“The old paradigm which was reductive to medical condition has presented disability as the result of a deficit in an individual that precludes him/her from performing functions and activities...The new paradigm is integrative and holistic and focuses on the whole person functioning in an environmental context.”

U.S. Department of Education, 2000



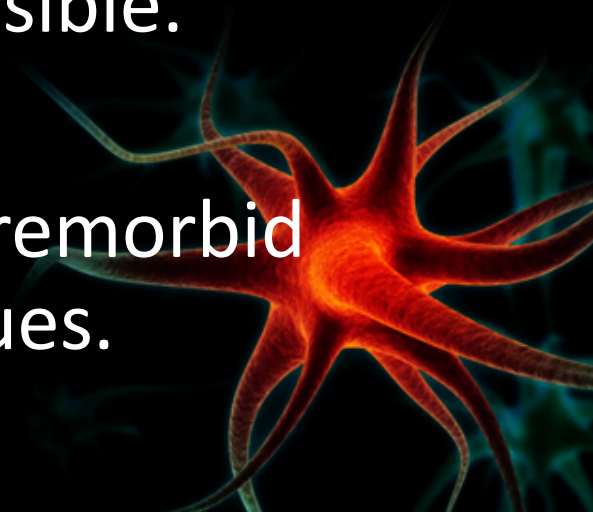
Research & Outcomes

Our Values That Affect Research,
Outcomes and Our Interpretations

1. Attitudes
2. Sentiments
3. Interests
4. Preferences
5. Subjective view of worth

Research Designs Should Address

1. Clear specifications of the injury and sociodemographic factors.
2. Details of treatment methods.
3. Standardized and other accepted outcome measures (e.g., ecological perspective).
4. Use of control group when possible.
5. Use of multiple sites.
6. Exclusion of consumers with premorbid history of CD or psychiatric issues.



Research, Treatment & Challenges

1. Which functional domains chosen for treatment are most important for a good outcome?
2. How do we decide which criteria to use in determining whether an outcome is acceptable i.e., value justifies the cost?
3. With what frequency should the desired outcome occur to justify allocating the treatment?
4. Given the outcome will be beneficial, at what point is it deemed financially excessive?



Participatory Action Model (PAR)

Benefits

1. Reinforces autonomy and beneficence.
2. Tate & Pledger state, “Research and the knowledge and products generated from research bear little importance if they do not involve and benefit or have meaning for consumers.”
3. Allows consumers to be partners rather than participants.
4. Allows consumer to experience empowerment, mastery and social acceptance.



Example of Success

Examined impact of person centered information on consumer satisfaction. Spent 29 days in intensive care before admission to TBI unit.

Results

1. Consumers given personal information exhibited greater effort in physical therapy.
2. Made more improvements in functional independence.
3. Were more satisfied with the rehabilitative treatment.
4. Concluded cognitively impaired individuals can benefit from treatment designed to enhance their sense of control and personal involvement.
5. Medical model vs. Socioecological model of research.

Summary

1. Have talked about autonomy
2. Looked at capacity and considerations in assessing
3. Proposed questions related to beneficence
4. Considered family involvement
5. Examined research, outcomes and potential bias
6. Pushed ourselves to think.

Questions?

Thank You!

Suggested Readings

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- Pegg, P.O., Auerbach, S.M., Seel, R.T., Buenaver, L.F., Kiesler, D.J. & Plybon, L.E. (2005). The impact of patient-centered information on patients' treatment satisfaction and outcomes in traumatic brain injury rehabilitation. *Rehabilitation Psychology*, 50(4), 366-374.
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