Ethical and Cultural Issues in Brain Injury Rehabilitation

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What is Rehabilitation

All things to all

- Several definitions around
- Several concepts
- Model variance is vast (Medical / Social / acute / community based, etc)
- Standardization so far has not been possible
- Limits understanding
- Limits uniformity
Definitions of Rehabilitation

► All means aimed at reducing the impact of disabling and/or handicapping conditions and at enabling a disabled person to achieve optimal social integration (Cultural, Vocational and Religious)

► Definitions of Rehabilitation on the Web:
  ► Comprehensive program to reduce/overcome deficits following injury or illness, and to assist the individual to attain the optimal level of mental and physical ability.
    www.tr.wou.edu/tbi/r.htm

► A process aimed at enabling persons with disabilities to regain and maintain their optimal physical, sensory, intellectual, psychiatric, and/or restore functions or compensate for the loss or absence of a function or for a functional limitation. *The rehabilitation process does not involve initial medical care.* It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocation rehabilitation.
  www.wfmh.org/wmhday/sec3_pt3_4_glossary.html
Definitions of Rehabilitation

The process of providing a program of coordinated services, with the full participation of the individual with SCI to achieve physical, psychological, social, economic, and vocational potential. Rehabilitation is a dynamic process of learning to live with a disability in one’s own environment beginning at the moment of injury and continuing for the duration of one’s life. www.aascipsw.org/StandardsPSW/VI.htm

Comprehensive program to reduce/overcome deficits following injury or illness, and to assist the individual to attain the optimal level of mental and physical ability. www.dooronline.org/glossary.pl
Definitions of Rehabilitation

► Services designed to assist an individual in adapting to a loss of physical or mental functioning, or to restore normal functioning. Usually provided following an accident or illness, rehabilitation is often a time-limited benefit that is only authorized if improvement is expected within a short period.
[Link](www.nciom.org/hmoconguide/GLOSS31E.html)

► the restoration of some former ability or state of being or some more optimum condition.
[Link](www.scientology.org/wis/wisger/gloss.htm)

► the restoration of someone to a useful place in society
[Link](www.cogsci.princeton.edu/cgi-bin/webwn)

► the treatment of physical disabilities by massage and electrotherapy and exercises
[Link](www.cogsci.princeton.edu/cgi-bin/webwn)
Ethics

► What is ethics

- Motivation based on ideas of right and wrong
- The philosophical study of moral values and rules
- The study of general nature of morals and of the specific moral choices to be made by the individual in his relationships with the others
- The moral sciences as a whole, including moral philosophy and customary, civil, and religious law
- The rules or standards governing the conduct of the members of a profession: Medical Ethics
What is Culture

► Social or intellectual formation
► The totality of socially transmitted behaviour pattern, arts, beliefs, institutions and all other pattern of human work and thought characteristic of community or population
► A style of social and artistic expression peculiar to a society or class
► Common set of social and ethical values, beliefs and artistic expression of individuals committing them to integrated coexistence

“Together with their own sorts all shell fly
A Pigeon with pigeon and an eagle with eagle”
CULTURE

- Is emotive
- Is sensitive matter
- All believe theirs is the best
- Is imposed through social engineering and political process and by persuasion and coercion
- Demands are placed on the minority cultures in a society to adopt the dominant trends
Ethical Considerations in Brain Injury Rehabilitation

- Traditional Medical Ethics largely developed in the context of acute care and survival.
- Rehabilitation Ethics should and does have different emphasis:
  - Lifestyle re-integration
  - Moral value judgements and adjustments
Differences between the traditional ethics and rehabilitation ethics

- Respect for personal autonomy rather than patient autonomy
- Active treatment participation contract rather than passive acquisition model
- An educational or process model of consent rather than a contractual or event model
- An intimate role for the family that can blur the distinction between the family and patient
- Greater honesty about quality of life judgement
Case-based or case specific ethics

- Medical ethicist refer to case-based ethics as casuistry.

- Casuists claim that ethics is primarily a matter of attention to details to circumstances of the case.

- In order to launch and maintain the process of case-based ethics, rehabilitation service must become institutionally conscience and manage each case with in ethical framework that is true to the service user and not to the service provider.

- All rehabilitation teams should acknowledge that each case has some ethical issues.

- In each case the emphasis and considerations are largely around longer-term outlook and final outcome and judgements are required to be made in the context of several months or year or two down the line.
Ethical considerations in Brain Injury Rehabilitation

- Consent
  - How
  - Who (takes it / gives it)
  - When and how often
  - Validity
  - Review process
  - Voidance
Ethical considerations in Brain Injury Rehabilitation

► Surrogate Decision Making
  - Delegation
    ► How
    ► Who
    ► How long
    ► Review

► Decisional Capacity
  - Who assess it
  - When
  - Review
Ethical considerations in Brain Injury Rehabilitation

End of life issues

- Withdrawing life support
- Quality of life judgments
- Organ donation
- Religious beliefs
- Euthanasia
  - Passive
  - Active
- Judgment of suffering
Other Frequent Ethical dilemmas in Brain Injury Rehabilitation

- Discharge to a care facility rather than home because of high financial cost of care at home
- Dealing with brain injured behaviourally disturbed and aggressive patients
- Discontinuation of rehabilitation
  - Extinguish hope
- Informing agencies of patient’s true disability
- Informing agencies of patient’s actual capacity
- Dealing with the medico-legal aspects of rehabilitation (personal financial gains: Bigger compensation bigger specialist FEES)
Two Cases

► 52 year old man with severe brain injury secondary to cardiac arrest related hypoxia. Bed bound, tracheostomy, PEG, deep ischial pressure ulcer, limited movements in both arms and leg, severe unilateral facial palsy with exposure keratitis and dysarthria, nearly 17 stones in weight, unable to self-turn in bed, catheterized, faecally incontinent. Able to understand spoken language and fair recall. Very supportive wife.

- ?In the event of further collapse: resuscitate or not
- Advise family of poor outcome earlier on in the rehabilitation programme
- Discuss long-term care issues early including total dependency

► 44 year old. Severe head injury. Good physical and fair cognitive recovery. Independently mobile and self caring. Living alone. Mild to moderate memory problems. Some organizational and planning difficulties. Drove local bus. Now absolutely fixed on the idea of returning to driving his bus. No financial reason for this. Licensing Authority will not release the vocational driving license although he has been given permission to drive own car and is doing so without any problem. Risk of epilepsy in the region of 10% of the normal population. Unacceptable for vocational driving license. Becoming depressed because he can not return to work which he says was his biggest love in life.

- Should I or Should I not facilitate the process of return to work (Vocationally rehabilitate him to return to his previous job)
Ethical Considerations in Brain Injury Research

- A code of research practice based on Modern Western ethical thinking
  - May not be true to all

- The principles guiding humane, responsible and trustworthy research
  - Financial gains difficult to eliminate

- Publically acceptable research behaviour
  - Private!!!!

- The system of ethical control of research
  - Is it robust
Ethical Considerations in Brain Injury Research

Main Concerns

- Consent
- Assessment of risk
- Scientific integrity
- Conflicts of interests
- Privacy and confidentiality
- Protection of vulnerable populations
- Issues of equity and fairness
CONSENT

► Ethical and legal requirements of consent include:

- Information about the purpose, methods, demands, risks, and possible outcomes of the research
- Exercise of voluntary choice to participate.

► Participants with reduced capacity include:

- Children and young people
- Persons with an intellectual or mental impairment
- Patients in emergency or intensive care
- Terminally ill people
- Persons in dependent or unequal relationships.
Organizational Safety

- The Safe research culture can not be transplanted in all institutions
- All Hospitals do not have organizational Structure for research
- Not all Laboratories or Pharmacies are internally structured to manage research
- Clinical staff may not be research savvy

Ethical Responsibility

- We must look at the organizational safety of any research protocol in the Ethics committees
Scientific Validity

- Valid for the populations that the research is being conducted upon

- In a recent lecture to young researchers in the United Arab Emirates, I commented:
  - Ethical assessment of protocols must look into scientific validity for UAE population samples (avoid research that may lead to wrong conclusions)
Dualities and Conflicts

► Dualities may include:

- Relationships with industry, roles as clinicians and researchers, direct or indirect payments, potential non-pecuniary benefits from research

► Conflicts of interest occur when duties associated with two roles are contradictory

► E.g. responsibility to patients and to drug company

► When a conflict exists the conflicting roles must be disengaged.
Protecting the Vulnerable

► No time to go into details
► But general message is that the Helsinki and Paris Declarations must be adhered to
► In cases of brain injured patients special mechanisms must exist that should allow for extra protection
► The researchers must have a culture of self evaluation and over critical analysis of research behaviours
FAIRNESS AND EQUITY

► Research is essential
► It is needed to develop better treatment models for future
► However, the enthusiasm for research must not override the primary concept of fairness and equity for all.
  ▪ Both in terms participation and
  ▪ Drawing benefit from results
Impact of Culture on Brain Injury Rehabilitation

► Each child goes through a process of **enculturation** when he or she grows up in a culture.

► Children learn by observing the behaviors of people in their immediate surroundings, including the recognition of **symbols** specific to that culture.
Culture is all-encompassing and integrated

- Culture envelopes each of us, and touches every aspect of our lives.
- Culture is systematic and integrated (it is not a random phenomenon).
- Cultures teach us to share certain core values that helps shape the personality of the individuals within a culture.
Ethnocentricity

► We are all ethnocentric

- We value our systems and belief more than those of others
- We consider our values and beliefs to be superior to those of others
- We retain and conduct ourselves more comfortably with in our own systems and environments
- Hence the China Towns, Ethnic foods etc
- People migrate along with their baggage of beliefs, value systems, arts and literature
Health care Provider and Culture

- In a multiethnic and multi-linguistic society those in the business of providing health care must provide it to an individual in an appropriate and socially and culturally acceptable manner.

- There must be an emphasis on “getting to know the person with in the patient”

- In no other speciality of medicine this is more relevant than Rehabilitation
Rehabilitation programmes should always be individual specific and must cater for his or her personal, social, cultural, religious and vocational needs. Any programme which fails to treat the individual according to his or her specific personal and cultural requirements will fail to deliver a favourable outcome.
Cultural Considerations in Rehabilitation

- Can individuals be culturally, socially or religiously “naturalized” through a rehabilitation process
- Can a rehabilitation team judge what lifestyle is in the “best interest” of a particular individual
- Should Rehabilitation team encompass or exclude cultural divide
- Rehabilitation of individuals should be to the level of their previous capacity with in the context of their life style
- Respect and accept (not tolerate) all beliefs and attitudes
- Rehabilitation is not social engineering
- “TREAT” or “REFORM”
- Rehabilitation team’s internal culture must be about excluding and dismissing preconceptions
Cultural Considerations in Rehabilitation

- Ignorance is basis for all prejudice
- Educational programmes for rehabilitation teams to learn about the cultural profiles of the major ethnic populations within their health care district
- Rehabilitation teams need to include with in their processes, systems to learn about each patient’s specific social cultural and religious beliefs and requirements
- Learning about the *person with in the patient* will facilitate *re-emergence*
- Should there be an effort to call patients by their correct names? Is time spent on learning to pronounce names correctly time well spent?
- Personal profiling for each patient
Personal Profiling

His or Hers

- Daily routine prior to injury
- Specific habits
- Religious beliefs
- Mother tongue
- Preferred dress code
- Preferred food code
- Eating habits
- Toilet habits
- Social and family structures
- Sensitivities and emotional responses
- Taste in music, arts and literature
- Work and vocational responsibilities
- Interest and hobbies
Rehabilitation Tourism

- Patients are now traveling from far to receive rehabilitation in distant centres in the belief of better outcome.
- The private rehabilitation facilities are now catering for culturally varied clientele.
- But amongst the similar populations when living as immigrant or naturalized citizens may not have access to culturally adjusted model of rehabilitation. ? Money makes ETHICS!!!!
A Cultural Message

It is a responsibility of rehabilitation services to rehabilitate individual patients irrespective of their colour, race or religious background in the manner that is most suited to them, particularly in the context of their colour, race and religious beliefs. While it is unlikely that there is any one amongst us who does not harbour some kind of prejudice towards others it is imperative that such prejudices are kept external to all rehabilitation programmes. *It is not a role of rehabilitation team to naturalize an individual through a rehabilitation programme*
THANK YOU