LONG TERM OUTCOME AND QUALITY OF LIFE

Wednesday, May 9, 2001

INTRODUCTION: QUALITY OF LIFE - A MANDATORY OUTCOME MEASURE AFTER TRAUMATIC BRAIN INJURY

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Objectives:
1. Quality of Life.
2. BMBF Consensus Conference.
3. QoL Measures.

The outcome after Traumatic Brain Injury can be discribed by disease status such as morbidity, organ failure and injury scales, but in order to assess the patients full burden of illness it is necessary to include constructs that comprise the patients Quality of Life(QoL) - his psychological well-being, his social relations and his functional capacity. Once the patients physical impairments are treated, QoL thrusts into focus.
Even though Traumatic Brain Injury is a topic that has been extensively discussed in the literature for the last 10 years, publications on Quality of Life and TBI are rather rare.
An extensive literature review on Quality of Life after TBI Publications (Berger et. al., 1999) showed that a standardized approach concerning the domains that effect QoL (physical, psychological, social, functional, cognitive) cannot be found. The instruments used to assess QoL range from generic, via specific to modular measurements.
The Meran Consensus Conference "Quality of Life - Assessment in Surgery" (1990) and the BMBF Consensus Conference "Quality of Life after Multiple Trauma" (1999) tried to structure the field and develop a guideline for the assessment of Quality of Life. In accordance with the Berger paper the BMBF Consensus Conference found these deficiencies not only for Patients with TBI but also for TBI in Children, Patients with Spinal Cord Injuries and Patients with Multiple Injuries.
On TBI, the recent conference came to the following conclusions:
1. QoL is viewed an important part of outcome assessment, the position of QoL in regard to other outcome assessments in TBI has yet to be determined.
2. QoL should reflect the patient's view, which does not exclude obtaining the relatives' perspective on outcome. In TBI differences in perception may exist between patient, significant others, and health care providers.
3. QoL assessment in patients with TBI is not applicable during the acute phase, and is only feasible when patients have regained consciousness. QoL assessment in next of kin may be important in the acute phase, but no studies have addressed this issue.
4. Generic scales commonly used in QoL assessment may not capture all relevant parts of outcome perception in TBI. Specific modules or scales appear necessary

(generic as well as disease specific). Scales require further validation, norm and reference values need to be established (also in the specific instruments for TBI group).

Further studies are required that lead to the development of specific QoL-instruments in TBI patients. A working group has been set up to test currently available measures such as the EBIS etc. and to develop a validated measure which can be used as a standard instrument in upcoming studies.

References:

- *Berger E.; Leven, F.; Pirente, N.; Bouillon, B; Neugebauer, E. (1999). Quality of Life after traumatic brain injury: A systematic review of the literature. Restorative Neurology and Neuroscience; Vol. 14; 93-102.*
- *Neugebauer, E., Troidl, H., Wood-Dauphinee, S., Eypasch, E., Bullinger, M. (1991) Quality of life assessment in surgery: Results of the Meran Consensus Conference Development Conference. Theoretical Surgery 6:123-137*

MEANINGFUL MEASURES OF OUTCOME

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It is estimated that each year more than 20.000 Italians are left with physical and/or cognitive disabilities caused by traumatic brain injuries.
Rehabilitation professionals claim that appropriate therapeutic interventions determine positive changes in the patients' and families' lives, and improve the functional and social outcome of persons with TBI.
On the other hand, the complexity and variety of the TBI sequelae make the specific effect of interventions difficult to measure.
Significant short-term and long-term measures of outcome after TBI are needed, and are helpful in :

- Improving knowledge of prognosis;
- Predicting the patients' and families' needs;
- Evaluating and comparing the effectiveness of therapeutic interventions;
- Establishing guidelines about treatment;
- Facilitating the appropriate use of resources.

Relevant outcomes after TBI should be measured taking into account the perspectives of multiple subjects, including that of patient and families, professionals, purchasers, referral sources, providers, payors and the community at large. Outcome evaluation in TBI rehabilitation should not be based only upon a clinical-medical model, but should be viewed in a broader perspective, encompassing shared human needs and societal norms relating to specific values such as independence, participation and self-determination.
We will discuss some relevant issues related to defining and adopting measures of TBI outcomes which could be "meaningful" for all the involved stakeholders, and we will present some recent italian experiences in this area:

- *Need for uniform outcome assessment tools* - Sharing a common language is essential to communicate among professionals and other stakeholders, to compare results, to uniform clinical practices, and to provide knowledge based on a broad experience. In Italy, a minimal TBI data set has been proposed (1) to address these issues. It includes as outcome measures data about impairment, disability, handicap and quality of life.
- *Establishing and disseminating guidelines* - The development of guidelines about good clincal practices and desirable outcomes in TBI shoud be based upon the contribution of all the relevant stakeholders. A Consensus Conference (2) has been held in Italy in 2000, with the aim of estabilishing recommendations on the rehabilitation management of TBI patients and their families. Clinicians, patients and families, providers and policy makers were involved in this initiative.
- *Educational and training issues* - A shift in the way rehabilitation professionals

conceptualize and deliver care is essential to prepare rehabilitation teams for outcome-based and outcome-driven rehabilitation. Many educational experiences in this field have been carried out in Italy during the last years. Among these, the PEGASO project (3) was particularly innovative, as it involved rehabilitation professional as well as patients'families and community members.

- *Collecting outcome data on a broad population* - An uniform dataset for TBI rehabilitation and outcome evaluation is adopted in a national prospective study, which started this year in Italy. The aim of the study is to collect data in a nationwide perspective, to provide knowledge about the current rehabilitation interventions for TBI persons in our country, and to identify critical factors influencing outcome.

1. Gruppo di lavoro sulla Valutazione - Sezione S.I.M.F.E.R. sulla riabilitazione del traumatizzato cranio-encefalico. Raccomandazioni per la valutazione riabilitativa del paziente con esito di trauma cranio-encefalico. Protocollo di valutazione riabilitativa di minima per il paziente con esito di trauma cranio-encefalico. Giornale Italiano di Medicina Riabilitativa, 3:5-25, 1998.
2. Conferenza Nazionale di Consenso - Modalità di trattamento riabilitativo del traumatizzato cranio encefalico in fase acuta, criteri di trasferibilità in strutture riabilitative e indicazioni a percorsi appropriati - Modena 20-21 Giugno 2000 - Documento conclusivo. Available on the following website: www.simfer.it
3. P. Boldrini – Pegaso: una esperienza di formazione al lavoro in team riabilitativo. Atti del Convegno: Riabilitazione 2000, Bellaria, 1999

MELDING THE HUMAN SPIRIT AND MEDICAL EXPERIENCE FOR THE 21ST CENTURY (REDEFINING THE SELF AFTER NEUROLOGICAL INSULT)

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For almost 10,000 years, the medical community has been involved in the understanding of the human nervous system. From the time of the Edwin Smith Surgical Papyrus in the seventh century B.C. to the Nobel Prize winning work of Gilman & Rodbell in 1994, the intricacies of what keeps humans alive and functioning have been scientifically studied and socially observed.

Throughout the ages, literature and the arts have portrayed this progression from ancient medicine and healing to modern scientific technology. Seeking cures through medicine and potions was seen as early as 2100 B.C. in a prescription collection of a Sumerian physician. Practical remedies and regiments were described by Egyptian scribes of the New Kingdom in 1500 B.C. This was the beginning of the systematic process. The healer listened to the patient's description of symptoms, examined the patient, and put forth a diagnosis based on physiological theories.

Traditional concepts of sickness were seen as personal in two ways. Illness or disability was thought of as an affliction forced on someone by a sorcerer, witch, or a demon. They were also seen as a punishment for wrong doing. Therefore, healing needed something other than clinical judgement and procedure, and there was the rise of folk and tribal medicine or "mumbo jumbo". That is not a far cry from the stethoscope necklace, the white coat, or the placebo in modern medicine.

It would seem like the healing arts were moving from magic to science. How people are cured in the healing process has gone from the casting out of demons to modern technology where healing has now become an economic question. The goal has always been to heal, but the process to reach this goal continues to evolve.

The Greeks are really given credit for modern medicine beginning with Hippocrates in 400 B.C. The major focus was not to control nature, which is our modern day pursuit, but simply to study it. The brain was then identified as the seat of behavior. Before 500 B.C. the heart was considered to be the center of our soul and being. In fact, 5000 years ago the Egyptians, in the preparation of the body for the journey to eternity, removed the brain through the nose and threw it way, while keeping the heart and other organs in separate jars.

Religion and healing have been married to each other for centuries; healing vs. death are two of the oldest stories. Death, for the believer, meant rebirth as a new person.

Death for the medical community meant failure. The theist believes God is a conscious intelligence that rules the world. The belief in a Christ figure made the experience personal. This is the same complexity of the doctor as God - and the patient needing a personal relationship. The relationship between doctor or healer and patient, a very personal experience, has become much more complicated and somewhat alienating to all parties over the ages.

Christianity has always been a healing religion. Christ healed the lepers. At the Pool of Bethesda Jesus said to a paralytic, "Rise, take up your bed and walk." God - like powers given to the healer has created a relationship of the powerful versus the powerless. Who will speak for those who can't speak following neurological insult? The paralytic or leper could ask - the quadriplegic can ask - but what about individuals with brain injury who do not even know to ask because they fail to see their handicap?

Jesus healed the epileptic as depicted in "The Transfiguration" by Raphael (1517). Jesus was seen as the source of healing. It is interesting to note that epilepsy was seen as the sacred disease, with St. Valentine, St Sebastian, and St Vitus all assisting epileptics. Early on, diseases of the mind were seen in an almost spiritual way. As time marched on, understanding increased that the soul and the humanness of this spiritual being is defined by the mind or the brain. It is the brain that is the seat of our spirit, soul, emotion, and our cognitive abilities to understand ourselves as creative beings and the responsibilities that evolve from this. How then does the healer heal that part of the anatomy that literally defines the individual? Without a relationship between those seeking a cure and those responsible for healing, how can we expect the lives of those forever changed by neurological insult to be worth living?

We have addressed physical disabilities for centuries and have created new ways and environments to accommodate and expand possibilities. There is no wheelchair for a traumatized brain, there is no prosthesis that enables an individual with brain injury to think, feel, believe, love, and laugh like they did before. Science has been given tools as gifts to heal or cure, and modern medicine is a testament to that. But what are our tools to heal the very core of our being that has been damaged?

Modern medicine evolved with the goal of controlling nature. Our success at controlling nature has created a world of disabilities because of much higher survival rates. Mortals acquired God-like healing powers, but with human limitations. We struggle every day to defy mortality and end up failing and living with people who are handicapped. They remain handicapped because the environment and community around them have failed to integrate them. In fact, the community often seeks to shut them out and reject them as less than able. Both the community of abled and those disabled lose.

Throughout the years, a constant dialogue existed regarding who we really are. Voltaire said "What am I, where am I, where do I go, where did I come from? We

throw our minds across the infinite, yet we cannot for a moment know ourselves." It is imperative to explore these questions in order to formulate a perspective of healing.

Healers and the community need more than the goal of controlling nature and healing the body. The real question becomes, "what is the cure?" It is not simply restoring to wellness. Curing is creating a world where those who cannot be cured physically, emotionally, and spiritually can live and be excited about life. Medicine spends billions to cure the body without creating a community for those beyond the touch of modern medicine.

Individuals are left out of the equation as we continue to save those with neurological injuries from dying. Those components that make up our humanness - soul, mind, spirit, loving, believing, physical prowess, eating, communication, parenting - all become impaired following brain injury. Inclusion of the person with traumatic brain injury in the planning of the rehabilitation communities is essential.

Our science and technology provide us with impressive tools for healing but not for living. Technology will only work when all the needs of a person are met - emotion, spirit, body, and soul - in a community that once again adds dignity and richness to the healing and human experiences.

The great tragedy in brain injury rehabilitation is the failure of health care professionals to look beyond the physical and cognitive deficits. The emotional and spiritual components are usually significantly damaged. A loss of the individual spiritual center asks the question of the meaning of their existence. Adult relationships with loved ones, friends, and a Supreme being become severely compromised, yet our communities are insensitive to these losses.

The goals of a community that embraces individuals with neurological disorders include dignity, self respect, redefinition, and a voice. Dignity is not only for the individual but for the community in which they reside. The community must be one where individuals feel respect. Since the individual will never be the same, the community must allow for a redefinition of that individual as a person and for creation of a new person. The final goal for the rehabilitation is for each individual to have a voice regarding the quality of his or her life. These simple goals are what we all desire within the human experience.

References:

- *Porter, R. ed. Cambridge Illustrated History of Medicine. Cambridge University Press, 1996*
- *Carmichael, A. G., Ratzan R. M. eds., Medicine: A Treasury of Art and Literature. Hugh Lauter Levin Associates, Inc. 1991*

RETURN TO WORK: CURRENT PRACTICE, FUTURE DIRECTIONS

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Objectives:

1. To briefly review current practice and outcomes of vocational rehabilitation for persons with brain injury.
2. To describe barriers to vocational re-entry of persons with brain injury.
3. To discuss alternative approaches to vocational rehabilitation and how we measure success.

Unemployment following brain injury is common, with estimates as high as 70% to 80% (Ben-Yishay et al. 1987; Wehman et al. 1993). Factors associated with the likelihood of return to work following brain injury include severity of the injury, length of hospital stay, duration of post-traumatic amnesia; pre-injury education level, work history, substance abuse problems as well as personality variables; and specific problems resulting form the injury (West, 1995). The range of employment possibilities includes return to previous employment level, return to employment at a decreased capacity, supported employment, sheltered employment and volunteer employment. Thomas and Menz (1997 p vii) state "Securing and maintaining employment after brain injury is perhaps the most important outcome characteristic of successful treatment and rehabilitation programs after medical stabilization and the return to community living".

They note that, in addition to the economic benefit of returning to work, the very fact one is gainfully employed is therapeutic in itself bolstering self-esteem and conferring dignity. Supported employment for individuals with severe brain injury has been the focus of research for the past several years. The concept and its cost will be discussed.

Barriers to employment include personal issues outlined above and social issues including attitudes toward persons with disability and financial disincentives such as, in the USA, Social Security Disability allowances.

Alternative approaches to paid employment include volunteering and the Clubhouse model. The Clubhouse, an idea borrowed from psychiatric practice, has been successfully applied to individuals with brain injury as described by Jacobs, (1997).

References:

- *Ben-Yishay Y, Silver SM, Piasetsky, E, Rattock, J.(1987). Relationship between employability and vocational outcome after intensive holistic cognitive rehabilitation. J Head Trauma Rehabil. 2:35-48.*
- *Jacobs, HE (1997). The Clubhouse: Addressing Work-Related Behavioral Challenges through a supportive Social Community. J Head Trauma Rehabil. 12, 5:14-****

- *Thomas DF, Menz FE (1997). Preface, Editorial, J Head Trauma Rehabil. 12, 5:vii-ix.*
- *Wehman P, West M, Sherron P, Roah C, Kreutzer J. (1993). Return to work: supported employment stratedues, costs, and outcme data. In Thomas DF, Menz FE, McAlees DC, eds.Community-Based Employment Following Traumatic Brain Injury. Menomonie, WI: University of Wisconsin-Stout.*
- *West, M.D., (1995) Aspects of the workplace and return to work for persons with brain injury in supported employment. Brain Injury 9, 3:301-313.*

OUTCOME EXPECTANCIES OF PERSONS WITH BRAIN INJURIES FOLLOWING REHABILITATION: PERSPECTIVES ON EMPLOYMENT

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Return to work is often a primary goal of brain injury (BI) rehabilitation programs and is often the standard of success for evaluating vocational oriented programs. Several factors, however, render employment outcomes difficult to accurately define and report. These include the advent of various new vocational rehabilitation strategies, technology interventions, and work-related supports available for maintaining persons in community-based employment following the provision of vocational rehabilitation services (Thomas & Menz, 1997). Often, use of accommodations including job coaches, peer mentors, and other innovative employment strategies can blur the line between competitive, protected, and supported employment schemes. It is essential to define the necessary conditions to allow a person to return to community employment. Furthermore, it is the ethical responsibility of outcome reporters to describe special accommodations. To not do so can be misleading and could underestimate the resources and supports needed to assist a person with significant functional limitations after a BI to return to productive activities.

As employment outcomes vary widely as a function of unemployment rates, severity of disability, and support services, as well as a host of other moderating variables, attempting to compare the effectiveness of BI rehabilitation programs in promoting return to employment becomes even more complex. Employment characteristics of importance in evaluating the nature and success of employment outcomes of persons with a BI who obtain vocational rehabilitation services have been widely cited in the research literature, but are not consistently reported.

Some of the traditional outcome factors reported include information about the number of hours worked, wages earned, and the employment benefits received. Other factors that often are not included in employment outcome reporting are actually more important to the person served than income and employment benefits and relate to things that are less tangible and more difficult to quantify. Among these are: (a) satisfaction with the rehabilitation process as well as the job obtained, (b) suitability and acceptability of the work environment, (c) potential for advancing on the job, (d) the degree to which a person was empowered with the right to choose employment goals and services needed to achieve those goals, and (e) whether or not the person served has been accommodated adequately and reasonably at the work site to make them as independent as possible (Thomas, Menz, & Rosenthal, in press). Perhaps the most important factor to consider is whether or not there has been an improvement in a person's quality of life following involvement in rehabilitation and employment related services.

This presentation will highlight the findings of a research study that examined outcome expectancies of persons served by employment oriented rehabilitation programs in relation to outcomes achieved. The primary purpose of this study was to examine what consumers of rehabilitation services and their significant others felt were important features to consider in assessing rehabilitation outcomes of vocationally oriented programs. First, a study of the expectancies of a sample of stakeholders involved in community-based rehabilitation programs will be discussed. The findings of this study formed the basis for the Employment Outcome Instrument (EOI) used to collect data in the second phase of this research (Thomas, Menz, Hisman, & Radtke, 2001). Next, the pilot study data that identifies the nature of the employment achieved by persons served by a sample of programs studied will be presented. Primary attention will be paid to factors related to perceptions of the quality of the services and outcomes and satisfaction with the return to work experience.

A brief overview of the reliability and validity of the EOI will be provided including internal consistency reliability estimates. Information related to informed choice and satisfaction with services received and employment will be reported. Issues related to quality of life and economic benefits of employment will be the central features addressed. (This study was funded in part by a grant from the National Institute on Disability and Rehabilitation Research, US Department of Education, Washington, DC).

References:

- *Thomas, D.F. & Menz, F.E. (1997). Validation of the vocational assessment protocol. Journal of Head Trauma Rehabilitation, 12 (5), 72-87.*
- *Thomas, D.F., Menz, F.E., & Rosenthal, D.A. (in press). Employment outcome expectancies: Consensus among consumers, providers, and funding agents of community rehabilitation programs. Journal of Rehabilitation.*
- *Thomas, D.E., Menz, F.E., Hisman, K., & Radtke, J. (2001). Validation on the employment outcomes instrument: A research report. Manuscript in preparation.*

QUALITY OF LIFE AFTER BRAIN INJURY IN DEVELOPING COUNTRIES

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INTRODUCTION:

People in developing countries are facing the "Triple Burden" of Communicable diseases and nutritional problems, Non Communicable diseases and Injuries in a situation of limited health resources. The epidemiological transition in the past few years has resulted in the emergence of injuries contributing for significant mortality, morbidity, disability and socio-economic loss (1).

With lack of total information on the precise magnitude of Traumatic Brain Injury (TBI) and its various dimensions, Brain injuries in India and other developing countries are often a hidden, silent and an unrecognised epidemic. It is estimated that in India alone, nearly 1.5 million persons and 1.8-lakh deaths respectively are registered every year. Nearly 70-80% of these persons are males and in their productive years of life. Major causes of injuries are road traffic injuries (60-70%), falls (20-25%), violence (10%), work place injuries (5%) and others. An examination into severity of injury reveal that 70% are mild, 15-20% are moderate and 10% are severe in nature (2,3).

Information on follow-up and outcome of TBI are not available from developing countries. In a hospital-based study at Bangalore, nearly 42% were still recovering at 4.5 months after discharge. Examination as per severity indicated that 62% of severe, 45% of moderate and 25% mildly brain injured persons had disabling symptoms after a brain injury.

TBI affects all areas of an individual's life and also of the family. Apart from day-to-day problems in activities of daily living, information processing, cognitive performance, memory and communicative abilities, TBI also places significant burden on socio-economic living status of families due to direct and indirect economic cost (4). The survivor and their families often go through number of psychosocial problems with long-term diminishing productivity (5). Thus an individual who was healthy, normal, and productive becomes unproductive and a burden on the family. Limited data on post traumatic sequelae reveal that post traumatic headache, anxiety neurosis, memory problems, social responsibilities along with reasoning and judgement are the major problems encountered in the life of a person with TBI. In a study from Bangalore, post- traumatic epilepsy and severe locomotor problems was observed in 8% and 6% of TBI survivors. Behavioural problems ranging from depression to aggressive behaviours were noticed in 12% of patients. These problems disrupt the communication channels within members of a family and also with the outside world resulting in communication gaps and social isolation (6, 7, 8, 9).

The working status of individual reveal that nearly 50-60% had returned to their jobs and 10% were totally unproductive. Majority of TBI survivors, specially those with

moderate and severe injury had to change their existing jobs and shift to less skilled jobs, thus diminishing their production and earning potentials. Return to work is also influenced by severity of injuries and rehabilitative inputs. Among children, nearly 50% of seriously injured children were unable to attend to schools. Further, among those attending schools, 30-40% of them falls backward in academic performance resulting in diminished scholastic achievements. Parents and communities often label these children is scholastically backward and add additional pressure to improve their performance (3, 10, 11).

The economic burden on the family is still not clear and it is estimated that nearly 2% of the GDP is lost by developing countries because of road accidents alone. Even though the cost of managerial care for TBI survivors in developing countries is less compared with developed countries, the impact is significant of low-income societies. In a study from Bangalore it was noticed that nearly 8% of the families had spent more than $ 30,000 on medical costs alone in different centres (12).

A number of factors like age-sex composition of the population, socio-economic living standards, technological progress of societies, availability of rehabilitative programmes, contribute for the nature, burden and quality of life of TBI survivors in developing societies. The significant transfer of medical technology and development of indigenous technology for management has resulted in a major decline of death rates across centres; due to advances in internal care techniques, diagnosis technology and early surgical interventions. With these advancements, the scientific community has also realised the problem, need and quality of life among those recovering from TBIs. Recovery is also dependent on number of factors like age, physiological status, alcohol consumption, severity of injury and the intensity of rehabilitation services. Further, the mental constitution, pre morbid personality, emotional impact, work and family environments, compensation and litigation procedures, severity and location of brain damage and response to therapy determine the final outcome.

The current rehabilitation measures in India for traumatic brain injured persons is meagre and inadequate due to varied problems in facilities and manpower. A proper and systematic assessment of individual needs family resources and expectations and, availability of existing services is often the key to develop relevant rehabilitation programmes. Accordingly, the strategies have to be aimed at the level of individuals, families and communities.

At the level of the individual, before initiating any intervention, it is essential to systematically evaluate the current health status, instil self-confidence, obtain co-operation and involve family and community. It is essential to build up the training of the individual in a graded, stepwise manner that would help in assessing the progress of recovery. Several measures which needs to be considered are pharmacotherapy, occupational therapy, psychotherapy, speech therapy, strengthening and supporting activities of daily living, behavioural modification, cognitive retraining and social adaptation.

The only source of great strength and support for TBI survivors in India and other developing countries is the family. In the absence of health insurance and other modes

of institutional management, family plays an effective role in Indian communities. Families being the nucleus of all activities for individuals, family members need to assume the role of educators, therapists and role models. Counselling for family members will be of paramount importance in accepting the survivors over a period of time (12). Some TBI survivors with severe disability and multiple organ damage need to be looked after for the rest of their life. Apart from providing emotional stability, the family also has to identify alternate source of income, utilise available resources and help in promoting social interactions. Family also helps in developing internal adjustments and to develop favourable peer group interactions. The stigma associated with psychological problems needs to be eliminated by the family members. Family needs of head injured patients has not been extensively researched and reports on long-term needs are scarce. Families have informed that they need information about on medical care, patient's progress, emotional support, ongoing assistance in learning to deal effectively with patient and information on vocational and social role restoration.

Integration of the individuals into the community is a much more complicated task requiring support from the community at different levels. The acceptance of the individual by the community towards earlier roles and future designated roles will be very crucial in ultimate recovery of patients. Communities have to perform a variety of tasks in reintegration and require guidance and support from professionals. The district rehabilitation centres should be revitalised and its role expanded role expanded to include Neurotrauma rehabilitation during the coming years. The concept of community based rehabilitation using community resources is gaining momentum in India (13). Involvement of local NGO's for economic and developmental activities will be useful. Creating job opportunities for occupational and economic support will be a very vital activity in developing societies. Many of the survivor's feels excluded when they no longer play a key role in the family socio-economic process and have restricted participation in society. The quality of life of injured persons is poor, as the present state of preventive and rehabilitative services for traumatic brain injury is totally inadequate in developing countries like India. With the growing recognition that injuries are a major public health problem and preventable in nature, efforts are required for more applied epidemiological research, and its application towards realistic policies and sustainable programmes across the world. Existing and forthcoming programmes must undoubtedly be cost effective and socioculturaly acceptable. Time-tested interventions are available for prevention and what needs to be promoted is the "will to implement and evaluate" for improving the quality of life of survivors.

References:

1. *Gururaj G: Injuries - A major hazard to health in: State of people's health in Karnataka (Eds) Francis CM. Voluntary Health Association of Karnataka, 1997: 139-149.*
2. *Channabasavanna S M, Gururaj G, Das B S and Kaliaperumal V G: Epidemiology of head injuries in Bangalore, National Institute of Mental Health & Neuro Sciences - Karnataka State Council for Science & Technology, Bangalore, PR/3/1993.*

3. *Gururaj G: Epidemiology of traumatic brain injuries: Indian perspective. Paper presented at the WHO - CAMHADD International conference on Understanding, Prevention and Treatment of brain damage due to Neurotrauma, Bangalore, Nov. 1994.*
4. *Levin H S, Grossman R g, Rose J E and Teasdale G. Long-term neuro-psychological outcome of closed head injury. J Neurosurg, 1979, 412-422.*
5. *Sabeshan S and Athiappan S. Families of Head Injured patients, their attitudes, experienced burden and psychopathology. Indian Council of Medical Research, New Delhi, 1987.*
6. *Johansson E, Ronnkvist M and Fuglmeyer A R. Traumatic Brain Injury in Northern Sweden. Incidence and prevalence of long standing impairments and disabilities. Scand J Rehabil Med, 1991: 23(4), 179-185.*
7. *Buchmann B, Kaufmann M A, Scheidegger D and Gratz O, Severe cranio cerebral injuries: Northwestern Switzerland 1984-1989. Schweuz Ned Wicgebscegrm 1991: 121(7), 214-220.*
8. *Annoni J M, Beer S and Kesselring J. Sequelae of severe cranio cerebral injuries. An epidemiological study in the canton of St. Gallen Schwaiz Med Schenscher, 1992: 16, 207-213.*
9. *Michaud L J, Rivara F P, Grady M S and Reay D T. Predictors of survival and severity of disability after severe brain injury in children. Neurosurgery, 1992: 31(2), 254-264.*
10. *Sabeshan S and Natarajan M. Long-term outcome following head Injury. J. Indian Med. Assoc. 1993: 91(2), 37-39.*
11. *Di Scala, Grant CC, Nrooke MM and Gans B M. Functional outcome of children with traumatic brain injury. Agreement between clinical judgement and the functional independence measure. Am. J. Phys Med Rehabil. 1992: 71(3), 145-148.*
12. *Krishna Reddy N: A Comparative study to understand the efficacy of family intervention programmes in head injury cases. PhD thesis submitted to Bangalore University, 1992.*
13. *Pandey R S: Research and evaluation of community based rehabilitation - Experiences of Government of India, ActionAid Disability News, 1993:4(2).*
14. *Gururaj G . Needs assessment of Traumatic Brain injury survivors in Bangalore. ActionAid Disability news 2,1997,34-42.*

FREEDOM OF MOVEMENT FOR EVERYONE

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"Automobile" means freedom of movement: a phrase used more and more today, that acquires significance and particular emphasis if it refers to the right to move belonging to more than 500 million people in the world, according to an estimate by the World Health Organisation, who have motory difficulties.

One can add to this general reduction in mobility the difficulty today linked to a certain moment in life and above all to the old age, that make up an ever growing percentage of the population.

Given this scenario, to ensure the individual right to move to a greater number of people becomes the primary social responsibility of a car builder.

This for Fiat Group is not just a statement of intent but is a firm belief that finds the answer in the "Autonomy Program", established in 1995: the first and largest program in the world dedicated to individual mobility promoted by a car builder and private company.

This Program is destined not only to promote the sale of specially adapted cars, but in the first place to offer studies and services to aid the disabled in the often arduous battle to obtain special driving licences.

To do this Fiat Auto has created a chain of organisations, called "Mobility Centres", where a team composed of a doctor, a physiotherapist, and a driving instructor accurately evaluate the driver's psychometric abilities. The originality of this service is that the evaluation is carried out looking on the "positive side", that is trying to exactly establish the effective "ability" to drive, and not, as often happens in official bureaucratic practice, the ability to "not" drive".

This is why the "drive simulator" occupies a central role amongst the instruments used in tests by the centres.

Over the last 5 years, using this simulator, it has been possible to objectively analyse people and to create a unique and precious database, rich in compatible and contrasting elements also in scientific terms.

From these studies useful information has emerged regarding people's psychometric abilities, in particular:

- The visual angle limits (successively determined by a true and real test on the visual field);
- The reduced reaction time to audio-visual stimulus;
- The limits to the range of movements required for various manoeuvres;
- The use of various driving systems to facilitate actions.

These centres have a pool of cars with different models and different transformations and a workshop where the vehicle can be prepared both to drive and to transport.

Driving the car on special circuits closed to traffic, our customers try the different transformations with the aim to test their own abilities.

Thanks to the multi-skilled and flexible structure, most centres propose a series of extra services: from legal and fiscal consultation, to help in job placement, to help in booking visits, required by law, with the medical examining board to issue a driving licence.

To book an appointment at one of the centres is easy, by phoning the toll-free number from anywhere in Italy 800-815015 or visiting the website www.fiatautonomy.com that offers a great amount of information and services, including the opportunity for the blind to navigate on the network without barriers, who are naturally interested in knowing the best transport solutions.

The Autonomy Program not only helps disabled people approach the automobile but also track them for as long as they are owners of a private means of transport.

A program therefore complete and successful behind which lies a hidden network of fine tuning of products and services and of synergy between all the companies of the Fiat Group who are part of the Autonomy Program: Iveco, Case – New Holland, Magneti Marelli, Fiat Research Centre and Toro Insurance.

The Italian culture of the Autonomy Project has been exported to almost all European countries, even in South America, adapted perfectly to the specific local conditions.

Getting back to specifically talking about the automobile, as well as studies on technologically advanced apparatus to aid driving newly produced cars, FIA worked on an articulated range of transformations and accessories based on international disability codes.

Apparatus conceived by a partnership with highly qualified coach-builders at international level.

The range of transformations include brake, clutch and acceleration apparatus without the use of pedals; electrical steering wheel functions also with infra-red waves, differentiated steering wheel gripping, "pedal" instruments to manage controls with the lower limbs, adaptations to the pedals to bring them closer to the driver, transformations that substitute or modify the gear stick, handbrake modifications, acoustic signals by pedal, vocal windscreen wiper, horn, lights and indicator commands. Whilst the accessories go from winches and wheelchair loading systems to revolving chairs co-ordinated with those in series production, from sliding doors to a single lever that manages braking speed, horn and indicators, to systems that allow direct wheelchair entrance to the driving seat.

All this is produced in this context that thanks to information technology is evolving with surprising rapidity.

In a short time automobiles, integrated in an efficient transport system will make mobility always safer, easier and free.

In the next few years new self-command apparatus will be installed, interacting with the surrounding environment, until the complete automation of many functions, including, one day, driving.
Also the scenario in which automobiles move changes rapidly. All the information and high technology systems, with Internet in pole position, consent enormous developments and offers the possibility of a continuous exchange of relationships and communication between the automobile and the outside world.

Research is constantly trying to render vehicles more intelligent and safe.

On the one hand, vehicles are built with radar and anti-collision systems that allow visibility in the fog, with cruise control to guarantee relaxed driving, on the other hand, with the increase in communication possibilities, navigation systems are developed connected to services in real time, to medical and sanitary assistance and to breakdown services, to specific and general information using the potential of Internet.

The future of the automobile is to guarantee more and more, without discrimination, mobility to everyone. And Fiat Auto are proud to count on disabled people amongst their best customers.

LIVING WITH A LIFELONG DISABILITY

Barbara A. York, a 9 1/2 year survivor of a traumatic brain injury

The term "lifelong" is appropriate to describe the challenges that a person may face when a life-changing event occurs. For many persons who have sustained a brain injury and their families, it is often the ending of the life known previously, and the rebuilding of the new life ahead. But "lifelong" does not have to mean a life without meaning and purpose. Barbara York, a survivor of a traumatic brain injury, will discuss the many challenges she has overcome in the 9 1/2 years since her motor vehicle accident, as well as suggestions for how others may improve their level of functional integration within their respective communities. Ms. York will share her experiences in rebuilding a functional life with meaning and purpose in this informative and inspirational personal testimony.