

3rd Session

**OUTCOME
AND QUALITY OF LIFE**

Tuesday, May 8, 2001

ORAL PRESENTATIONS





EARLY AND LATE FACTORS PREDICTING RETURN TO WORK AFTER TRAUMATIC BRAIN INJURY

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Objectives:

1. Considerations about the value of prognostic indexes predictivity.

During a ten-year period (March 1990-September 1999) 438 patients suffering from a traumatic brain injury (TBI) were admitted to the Don Calabria Hospital Rehabilitation Unit. Follow-up data were available for 354 patients (81%), 66 were lost, 16 deceased.

Methods: Aim of this study was to attempt to establish if factors such as Glasgow Coma Scale (GCS), post-traumatic amnesia (PTA) and Glasgow outcome scale (GOS) correlated to the return to work. The relationship between both GCS (first day) and PTA versus GOS at 1 year after injury was evaluated for all patients of this series. For those who were employed (or employable) before injury (288) the correlations between GCS, PTA and GOS (at 6 months) versus return to work were also investigated.

Results: This study indicates that GCS had not a predictive value for occupational outcome, mostly for patients with low initial scores: favourable results in re-employment were not uncommon even in this patients. Low GOS scores at 6 months positively correlated with the return to work (52% in this series). PTA turned out to be predictive of both impaired or impossible re-employment, especially for those patients with prolonged amnesia (more than 60 days). Results of this study also indicates that patients with residual physical impairments after TBI carried a higher occupational risk as compared with patients with cognitive impairment only.



THE EFFECTIVENESS OF ACTIVE LISTENING TRAINING WITH ACQUIRED BRAIN INJURED ADULTS

1. **Bruce A. Linder**, PhD (Registered Psychologist), Pryor, Linder, & Associates, McMaster University, Brain Injury Services of Hamilton, Oakville, Ontario, Canada
2. **Pam Lawrynowicz**, B.A., Peel-Halton ABIS, Peel Behavioural Services
3. **Kim Harrison**, B.A., Peel Behavioural Services

Objectives:

1. Participant will learn about an effective training procedure for teaching active listening skills (ALS) with ABI adults.
2. Participant will learn about how memory and intellectual factors influence ALS learning.

This study evaluated the effectiveness of a social skills program designed to teach adults with acquired brain injuries active listening skills. Seven adults (age 24 – 41 years; four males, three females) with brain injuries (5 to 19 years earlier) participated in 10 to 15 two-trainers-on-one sessions teaching three component skills of active listening (paraphrasing, checking for understanding, and inviting for more information) as part of a program teaching interpersonal problem solving skills. Pretest-posttest data was collected as well as session-by-session training data. Pretests and post-tests involved videotaped interactions between the subjects and a significant-other attempting to solve a relationship problem. Standardized verbal IQ (WAIS-III) and memory (WMS-III) testing was also conducted. The training involved 1-hour sessions twice per week in which the subjects practiced three active listening skills over 60 trials per session to videotaped and live stories constructed to gradually expose the subjects over three phases of training to expressive communication that might occur in real interpersonal conflict situations. The trainers provided modeling, corrective feedback, and reinforcement for performance. Session data showed that the program was highly successful in teaching all subjects independent active listening skills to an average of 94% success. Post-test results showed that the skills generalized successfully on an overall average of 37% of the communicycles occurring in natural interactions, but only under conditions in which visual cues were present, and for those with verbal IQs greater than 85 (63% of communicycles). The results confirm the effectiveness of performance-based multi-trial training programs in teaching social skills.



GENDER DIFFERENCES IN TRAUMATIC BRAIN INJURY: SEVERITY, RECOVERY, AND OUTCOMES

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 2. *Jean Basom*, BSN MBA
 3. *Amelia Unione*
 4. *Christian G. Zimmerman*, MD FACS
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Objectives:

1. Develop a gender specific characterization of TBI.
2. Illuminate gender differences that affect TBI recovery.

There is controversy regarding whether or not it is necessary for research to be gender specific. In the past, the common belief was that treatment approaches were the same for everyone, regardless of the patient's sex. Recent medical research has illuminated significant problems when male specific research has been generalized to women without benefit of women being included in the studies. Specific to TBI, recent research debates whether men or women have a TBI recovery advantage. Some postulate that estrogen and progesterone have neuroprotective effects that may improve outcomes in women^{1, 2, 3} while others argue that men have better outcomes⁴. To investigate gender differences, we tracked 190 [N=190 M=133, F=57] participants in a longitudinal TBI study, actively monitoring patients from the onset of injury, through rehabilitation and community reintegration. Measures included, (1) neurocognitive tests; (2) patient demographics, including education, marital status, substance involvement, use of protective devices, and surgical interventions; (3) hemorrhagic severity and location; (4) specific surgical/treatment approaches; (5) length of coma and level of awareness; (6) daily observations; and (7) outcome scores. We report a characterization of men versus women who sustain TBI, highlighting gender similarities and differences. For example, our findings indicate that women suffer from more severe injuries than men and subsequently experience worse outcomes. Further analysis reveals specific factors contributing to these findings. Information gleaned in the analysis of patterns of gender similarities and differences facilitates the process of providing the best possible care and outcomes for all patients.

References:

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3. Groswasser Z, Cohen M, Keren O. Female TBI patients recover better than males. *Brain Inj*. 1998;12(9):805-808.
4. Farace E, Alves WM. Do women fare worse: a metaanalysis of gender differences in traumatic brain injury outcome. *J Neurosurg*. 2000;93(4):539-545.



DRIVING AFTER BRAIN INJURY

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2. **A-K. Schanke**, Sunnaas R. H. Senior Psychologist, Sunnaas Hospital, Oslo, Norway
3. **P.E. Østen**, Senior Consultant, Sunnaas Hospital, Oslo, Norway

Objectives:

Brain Injury, Driving Behaviour and Accidents.

Description: Little is known about driving fitness after brain damage. The study is a follow-up on 62 brain injured patients, 49 males and 13 females, mean age 50 years, who 15 months previously were held suited for driving after a medical, neuropsychological and on-road assessment. 36 had CVA (58%), 15 TBI (24%) and 11 had other neurological diseases.

Methodology: A questionnaire was sent asking for accidents and yearly driving distance pre- and post-injury, perceived alteration in traffical behaviour and driving fitness post-injury.

Conclusion: During the last 5 years pre-injury 13 patients had been involved in 18 accidents. During the 15 months post-injury, 9 patients had been involved in 10 accidents. Extrapolating accident rate to 5 years post-injury, no significant difference was found. Patients with TBI had significantly more accidents post-injury than patients with CVA. No statistical difference in accidents was found in regard to lateralisation of lesion. Those involved in accidents were younger, had been driving for a shorter time, were taking less precautions and had cognitive impairments such as defecits in executiv functions.

References:

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PERSONS WITH ACQUIRED BRAIN INJURY LIVING IN A FAMILY SETTING: THEIR VIEW OF COMMUNITY INTEGRATION

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3. *M. Gheysen*, RN, Bsc, MSc, Belgium

Objectives:

1. Family support and involvement for clients with an Acquired Brain Injury is considered as necessary towards community integration. According to McColl, (1989) successful community integration depends from the degree of independence, their participation in activities and the quality and quantity of social contact.
2. The motivation behind this study was a desire to gain access to the experiences of ABI-clients and their families' re-integration in the community. Previous experience with quantitative approaches had led to dissatisfaction with the person's qualitative perspective of re-integration.

Design

An existential-phenomenological approach was used in an attempt to reconstruct clients' experiences as reported in their own words. The interpretative framework was guided by McColl (1998). The aim of the study was to provide a constructed reality of clients' experiences that 'is as informed and sophisticated as it can be at a particular point in time'.

The interview focused on following items: capacity of adaptation, feeling of acceptance, geographical orientation, strengths of relations, capacity to make contact, productivity, leisure time, independence and life situation.

Results

By listening to the interviews, the researchers identified strongly negative experiences couched in terms of loss, namely loss of self identity, autonomy, loneliness and a lot of misunderstanding between clients and their families caregivers. Clients with ABI living at home are not registered and felt ignored as a group with specific needs. They identified a big gap between institutional care and home care. Very few families receive adequate professional support at home. Family members indicated a lack of information, the amount of paperwork and the fragmentation of the 'care and support' services as barriers for community integration.

Conclusions and Implications

The conduct of this study clearly raised dilemmas in the re-integration of clients with an Acquired Brain Injury. Change will not occur until resources are relocated, live and work conditions are optimised and health workers and clients are valued and motivate to invest their time in re- integration in the community. Empowering clients, families



and health-workers through democratic process in their decisions can only challenge this. Regional case managers and/or a co-ordination centre could assist clients diagnosed with ABI and their family from the beginning. Those case managers could guarantee the continuum of care across institutional borders and reduce feelings of incomprehension and loss. In addition an emancipatory research process that supports re-integration in the community may facilitate change.

References:

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- McColl M.A. (1998) *The definition of community integration: perspectives of people with brain injuries*. *Brain Injury* 12:1, 15-30.
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INTENSIVE NEUROREHABILITATION IN THE NETHERLANDS: RESULTS OF A FOLLOW-UP STUDY ONE AND THREE YEARS LATER

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3. *Anke Bouma*, Rijks Universiteit Groningen, The Netherlands

In the Rehabilitation Centre of Amsterdam, a program for Intensive Neurorehabilitation, following the holistic principles, has been carried out since 1995.

This day treatment program, which lasts 16 weeks, focusses on the the cognitive, behavioural and emotional consequences of head injury. Increasing awareness of deficits and building up of social competencies are important aims of the program. The program is built on the principles which have been laid down by Ben-Yishay, Prigatano and Christensen.

In cooperation with Prof. Dr. Anke Bouma, Rijks Universiteit Groningen, an evaluation study has been carried out. Patients were tested neuropsychologically, and they filled in questionnaires on cognitive, behavioural, emotional and social functioning, at four moments: before entering the program, immediately after finishing the program, one year and three years later. Significant others (mostly partner or parents) also filled in questionnaires in which they rated the cognitive, behavioural, emotional and social functioning of the patients, at the same moments as described above.

The results of the follow-up study of the first two groups who followed the program, one year and three years after finishing the program, give support for the effectiveness of the program. The most significant results are found in the behavioural and social domain. Neuropsychological testing shows only slight changes in scores before and after the program.



FACTORS INFLUENCING CAREGIVER BURDEN AND FAMILY FUNCTIONING AFTER HEAD INJURY

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Objectives:

1. To investigate the characteristics of the head-injured patient and carer that influence family functioning and perceived burden of care.

Method: Questionnaires were distributed to 60 caregivers with a response rate of 62%. Patient and carer factors were investigated in relation to carer burden and level of problems in family functioning. These were patient demographics and injury information, carer characteristics, head injury sequelae, satisfaction with support and financial well being. Caregiver burden and family functioning were measured by asking carers to rate the frequency with which they had experienced a number of problems in the last six months.

Results: In a multivariate analysis (ANCOVA and Scheffe post hoc tests), age of the caregiver and patient, intellectual and behavioural problems and the patient's relationship to the caregiver were found to be associated with caregiver burden. Increasing age of the patient was positively associated ($F=10.2$, $p=.01$) with increased caregiver burden while age of the caregiver was negatively associated ($F=6.84$, $p=.03$). A higher degree of reported behavioural problems was positively associated ($F=11.96$, $p=.009$) with caregiver burden. Factors associated with family functioning were physical ($F=9.11$, $p=.01$) and behavioural ($F=4.53$, $p=.05$) problems in the patient, financial situation ($F=3.81$, $p=.04$), length of time unconscious ($F=9.01$, $p=.01$) and caregiver burden ($F=19.89$, $p=.001$). Time since injury was not significantly associated with level of caregiver burden or family functioning.

Conclusion: These results highlight domains where carers experience most difficulty and can inform the development of targeted evidence based interventions.



SELF-SUPPORT GROUPS FOR THE RELATIVES OF BRAIN INJURED PATIENTS ADMITTED TO A REHABILITATION UNIT

1. *Maria Rita Magnarella*, Psychologist

2. *Paolo Boldrini*, Medical Doctor

Unità di Alta Specialità Riabilitativa per Gravi Cerebrolesioni, Ferrara, Italy

Objectives:

1. To implement and to evaluate the impact of a self-support group for relatives of persons with a brain injury admitted to a specialized rehabilitation center.

Traumatic brain injury is a catastrophic experience not only for the person, but also for the family. We thought that, besides the support and information provided by the professional members of the rehabilitation team, the development of peer-support initiatives would have been helpful in addressing the needs of family members.

Therefore, we implemented a self-support group for the relatives of the brain injured patients admitted to or discharged from our rehabilitation unit.

The meetings of the group are held every two weeks; they last 60 to 90 minutes. The participation of family members is on a voluntary basis. A professional member of the rehabilitation team attends the meetings; her role is to give organizational help, to facilitate the communication among the members of the group, to provide information when needed.

The group started on November, 1999; up to December 2000, 27 meetings have been held; the average number of participants is 12, (ranging from 9 to 15).

The topics discussed during the meeting varied from the emotional difficulties experienced by the family members, to the financial and other practical problems that they have to face after their relatives' illness.

An interview was given to a sample of family members; their answers showed that the self-support group is helpful in mitigating the feelings of loneliness and helplessness, and in facilitating the adjustment to the relatives' disability, by sharing thoughts with other persons involved, and finding out other people's perspectives.

The self-support group is also useful in getting help with practical issues, in gaining understanding, and in establishing long lasting relationships which could provide support even after discharge.



LONELINESS, SOCIAL SUPPORT AND PSYCHOLOGICAL WELL-BEING AFTER BRAIN INJURY

1. **Robert J. Rauch**, PhD, Thompson House Hospital, Down Lisburn Trust, Lisburn, UK
2. **Susan M. Ferry**, DClInPsych, Queen's University, Belfast, UK

Objectives:

1. To investigate the presence of loneliness 2 years post-injury.
2. To examine the relationship of loneliness to social support and psychological well-being.

Emotional and psychological changes that occur following an acquired brain injury (ABI) are considerable and have a significant impact on rehabilitation 1, 2. The literature on loneliness following brain injury is limited. In other populations, loneliness is related to anxiety, depression and suicide 3, 4. This study investigated the experience of loneliness in a community sample of people at least 2 years post injury (ABI) and examined the relationship of loneliness to social support and psychological well-being.

Design: Single group cross-sectional. The subjects (N=24) were engaged in a community brain injury rehabilitation service.

Measures: UCLA Loneliness Scale – Version 3; Wimbledon Self Report Scale; Hospital Anxiety and Depression Scale; Social Support Questionnaire, SSQ6; Social Network Interview Schedule.

Results: 42% of the sample had clinically significant mood disorder and 21% were considered lonely. Loneliness was related to psychological well-being ($r = .63$, $p = .001$); total size of social network ($r = -.42$, $p = .039$) and number of support providers ($r = -.54$, $p = .006$). Stepwise multiple regression showed depression and number of support providers significantly predicted loneliness ($f = 12.4$, $p < .001$). Total network size was related to ($r = -.57$, $p = .004$), and significantly predicted, psychological well-being in a stepwise multiple regression analysis ($f = 10.5$, $p = .004$).

Summary: Social network and support variables are predictors of psychological well-being and the experience of loneliness 2 years following ABI. The potential role of social network and support interventions in community based rehabilitation are discussed.

References:

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5. Trout, D.L. (1980) *The role of social isolation in suicide*. *Suicide and Life Threatening Behaviour*, 10, 10-23.



TBI: QUALITY OF LIFE'S GREATEST CHALLENGE

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2. *D. Peter Reedy*, MD
3. *Joanne Hash*
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Objectives:

1. Identify elements that constitute appropriate quality of life.
2. Determine differences between patients' perspectives and the families' perspectives of post-injury quality of life.
3. Examine satisfaction with acute intervention decisions.

A universal definition of quality of life (QL) does not exist. Those familiar with a disabled lifestyle have different perspectives than those who are not. Everyday TBI forces thousands of people to contend with significant QL challenges. Encountering these issues on a daily basis compelled us to investigate perspectives of TBI-related changes in QL. For the purposes of these investigations, we defined QL as one's expressed satisfaction with life. Study 1 identified common elements that comprise an acceptable QL from the perspectives of 27 (11 female, 16 male) with TBI (mild or moderate disability). Five areas revealed striking differences in perspectives: (1) family versus the person who sustained TBI, (2) gender differences, (3) age, (4) relationships, and (5) spirituality. Finally, we investigated treatment decision satisfaction. Study 2 focused on the same issues but from the perspective of family members of 8 (4 female, 4 male) who sustained TBI that resulted in severe disability. Study 2 included a statistical analysis comparing findings from Studies 1 and 2 which revealed numerous differences such as satisfaction with treatment decisions. For both investigations, we created, tested, and administered two forms (patient, family) of a 35-question (ordinally scaled and open-ended) interview. We combined the interview data with a variety of other measures collected during hospitalization and community reintegration. Analysis approaches included Spearman's Rho, Pearson Chi-square, Somers'd, Kendall's tau, gamma, and regression analysis.



EXPLORING SELF-CONCEPTS AS SUBJECTIVE QUALITY OF LIFE OF PERSONS WITH BRAIN INJURY

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Objectives:

1. To identify the sources and basis of self-conceptions in persons with brain injury.

Objectives: This study is the first attempt to explore the self-concept of Hong Kong Chinese adults who have suffered from brain injury leading to various degree of cognitive deficits. In facing the changing world scene from labour-intense type of daily life and work, to more challenging information-based scenario in the new millenium, it is obviously that persons with cognitive deficits will suffer most in coping with these rapid changes. On one hand, their self-perception of own abilities and thus their independence would be much affected, thus challenging rehabilitation outcome. Moreover, cognitive rehabilitation programme aim to both alleviating their cognitive deficits and at same time strengthening their confidence in coping with cognitive disabilities. Thus apart from assessment the efficacy of cognitive interventions to specific cognitive problems such as attention, memory, problem solving and other higher cortical functions related to daily life, it is also crucial to monitor their self-concept which is itself a basic human cognition. Measurement of self concept ultimately may serve as important outcome measures of rehabilitation programme, in terms of peoples' internal perception of self and perception of one's self-concept in a social context, which are hampered by their cognitive disabilities.

Method: This study recruited 120 individuals with brain injury. The basis of their self-concept was explored and compared through probing, comparing, and contrasting their perceptions on different life aspects, by means of The Adult Source of Self-concept Inventory (ASSEI) Chinese Version (Elvoson & Fleming, 1989; Tam & Watkins, 1995). It was adopted to identify the sources and basis of self-conceptions in persons with a brain injury. The ASSEI requests each subject to rate each of the twenty items on ten-point (1-10) scales both the importance he or she attaches to and his or her satisfaction with 20 different areas of their life. The ASSEI questionnaire allowed quantitative comparisons on a standardised instrument of importance and satisfaction of self-concept facets often tapped by Western instruments. The ASSEI covered various aspects of the self-concept such as the physical, social, ethical, familial, and intellectual.

Results: Factor analysed responses of the 20 ASSEI items and revealed four factors with eigen values greater than 1.00. The four factors identified were named as Interpersonal Relationship, Personal Quality, Physical Self, and Personal Achievement.



The means and ranks of the ASSEI items were indicated by the subjects. The five most important life areas were family responsibilities, honesty, family relationships, law abidingness and physical abilities. The most satisfied were law abiding, honesty, family responsibilities, family relationships, and close relationships. Use Wilcoxon Signed-Rank Test to compare the rank order of the ASSEI importance and satisfaction ratings, it is found that that there was no significant difference in how the subjects ranked the importance and satisfaction of life areas ($Z=-0.15$ and 2-tailed Probability=0.83) except their abilities in various life aspects. The results showed the self-verification and self-enhancement tendency of the subjects in general. However, the subjects ranked their abilities as the fifth important life areas with the twelfth ranking in satisfaction. This actual-ideal discrepancy might cause significant negative impact to their overall self-concept. Moreover, the subjects' responses to the open-ended questions were consistent to these findings and thus further confirmed the important life domains of persons with brain injury.

References:

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DOCTORS AND LAWYERS WORKING TOGETHER FOR THE BENEFIT OF VICTIMS OF TRAUMATIC BRAIN INJURY: IN A MULTILINGUAL AND MULTICULTURAL SOCIETY

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2. **Sarita R. Schapiro**, PhD, Neuropsychologist, The Center for Family Development, Boca Raton, FL, USA
3. **Rosanne C. Martino**, M.A., Director of Medical Review, Medlaw-Assoc.com, Fort Lauderdale, FL, USA

Objectives:

1. Addressing brain injury from a legal perspective.
2. Neuropsychological sensitivity of linguistic and cultural differences.
3. Medical/legal corroboration for the benefit of the patient/client.

In certain parts of the United States recent immigration is changing the linguistic and cultural dynamics of American society. As the United States enters the 21st century, fluency in a language other than English, knowledge of recent immigrant cultures, and appreciation of native societal idiosyncracies become crucial to the effective treatment and legal representation of our patients/clients.

The cost of traumatic brain injury is estimated to be \$48.3 billion annually in the United States; hospital costs account for \$31.7 billion. Fatal brain injuries cost our nation \$16.6 billion annually. The majority of deaths or injuries from brain injuries is caused by motor vehicle accidents and falls.

This workshop will review how multicultural and multilingual considerations impact on the evaluation and legal representation of the individual who sustains a traumatic brain injury. Emphasis will be placed on reviewing the medical-legal distinction between mild, moderate and severe brain injury, the use of established and innovative diagnostic techniques, and specific legal considerations in representing the client. In addition, the special contributions of the neuropsychological evaluation that is sensitive to the unique culture and language of the client's country of origin will be discussed as it impacts on the legal aspects of the case.

References:

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THE ROLE OF THE EXPERT IN ABI CASES: THE LEGAL PERSPECTIVE

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Objectives:

1. To discuss the importance of expert testimony in a lawsuit, particularly with respect to acquired brain injury cases.
2. To review the legal preparation necessary with respect to the presentation of expert evidence.

Acquired Brain Injury patients often have a right to claim for compensation for their injuries and disabilities. Expert testimony is instrumental in a lawsuit as the evidence of an expert is given considerable deference in the decision-making process. The expert plays a key role in determining compensation and whether an individual will have access to services. The selection of the expert witness, the preparation of their report and the witness' ability to testify in a clear and credible manner are crucial. No matter how well-qualified the expert witness may be, there is no substitute for adequate legal preparation with respect to presentation of expert evidence.

This presentation will look at the role of the expert witness from the legal perspective, including:

- * what constitutes an expert witness
- * why should an expert witness be retained
- * what should be included in an expert report
- * the rules governing the admissibility of expert evidence
- * the types of evidence given (expert opinion versus non-expert opinion)

The relationship between legal counsel and health care providers will be emphasized. The inherent conflicts between the medical and legal system will also be explored, in terms of the role that each system plays in regards to the prognosis and rehabilitation of the ABI sufferer.

Ensuring that the ABI patient gets proper care should be the primary concern of healthcare practitioners and personal injury lawyers alike. Only through preparation and education can they work together to attain their common goal of providing the best possible care to ABI patients.

References:

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