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Abstract

A Traumatic Brain Injury (TBI) may result in brief, moderate, or lifelong physical, emotional, cognitive, behavioral, social and employment difficulties, extended unconsciousness, permanent disabilities, or death. The annual TBI incidence in the United States of 1.7 million people or more and the estimated 5.3 million people with TBI dwelling in the U.S. contribute to TBI being a grave public health issue. While the physician is typically considered the point person directing the medical care for an acute TBI, the key member of the health team should be the person with the TBI along with a family support person. A comprehensive approach to recovery should include early referrals to many other types of health professionals such as neurologists and other physician specialists, physical therapists, psychologists, speech therapists, etc. for early intervention and avoiding delays in healing that may result from subtle problems cognitive dysfunction, depression, or vision and other sensory system deficits. Simple tools such as a Care Notebook holding various care and treatment details as well as pragmatic strategies such as memory and communication tips for the person with the TBI and the physician (or other health professionals) should help the family stay abreast of the multiple treatments, medicine changes, appointments, and changing needs over time. In addition, a network of health professionals, community programs and e-resources are important to address the many different challenges toward recovery. A Traumatic Brain Injury (TBI) may range from a mild to a severe: bump, blow, jolt, or penetrating injury to the head that results in brain dysfunction. The impact of the TBI may range from a momentary mild brain dysfunction to a severe injury resulting in extended unconsciousness, permanent disabilities, or death. With 138 people in the United States dying daily from injuries that include TBI, the annual U.S. TBI incidence of 1.7 million people or more, and an estimated 5.3

Index terms—

anosognosia (decreased or lack of self-awareness) interferes with seeking professional help. The limited training of health and social service providers may impede progressive healing, especially after the healing of obvious injuries, i.e. fractures and lacerations, and continuation of obtuse, neglected problems such as in sensory perception i.e., subtle difficulties in smell, hearing, or vision. [4][5] [7][8] Yet based on an intensive study of the literature published between 1998 and 2004, Gordon et al. (2006) in their "State of the Science Review" compelled researchers and clinicians to fill the extant gaps of TBI knowledge particularly related to the complexity and heterogeneity of: the population, the injuries, the treatments, rehabilitation protocols, recovery, and barriers to fulfilling, productive lifestyles. 9,10 The purpose of this paper is to present an anecdotal model of strategies to guide others through "the dynamics of recovery from TBI". ??,p.344 The pragmatic strategies for the person with TBI, the family support person(s), and health and social service providers evolved from the post-TBI road to recovery and coping experiences of the second author, formerly a manager of a top fortune 20 company before sustaining a severe TBI seven years ago from a motor vehicle accident. Emphasis points to the importance of a comprehensive approach, being actively involved with the health team, having at least one family support

person, attending to the complexity of obvious injuries versus elusive damage, creating unique interventions that respect individual differences, accessing diverse resources, and reintegrating into community life. 9,10 I.

1 A Comprehensive Approach

Addressing a TBI should involve a comprehensive approach. The person with the TBI, as soon as possible, as well as a family support person (spouse, adult child, partner, etc.) should actively join with the various health professionals in the care planning, decision-making, and development of a network of resources to deal with the many steps leading to recovery. The person with the TBI, family support person, and health providers should pay attention to the specifics and the follow-up of tests, treatments, appointments, and referrals to other services, educational resources, and programs. a) Key Person on Health Team An important aspect of care and recovery is the relationship between the person with the TBI (the patient) and the physician. This relationship is especially critical initially because the physician is usually the first and ongoing point person to provide and guide medical care. As a result of the TBI, the patient is often in a state of Results from TBI may lead to brief, moderate, or lifelong physical, emotional, cognitive, behavioral, social and employment difficulties. The person with TBI may be more at risk for other health problems such as seizures, depression, falls and fractures, habitual self-medication with alcohol, or other chemical abuses. Accessing appropriate healthcare and other services over the acute and long-term steps toward healing present unique challenges to the person with TBI and the family support system, especially with subtle injuries, such as mild cognitive changes in emotional communication (associated with right hemisphere injuries), or faulty judgment and decision-making (associated with frontal lobe injuries). Sometimes the embarrassment of the person with the TBI or of turmoil due to the trauma, disrupted lifestyle, and several other related issues. For example, there may be trust issues because of a loss of sense of self. A severe cortical injury may lead to a complete loss of identity and cognitive dysfunctions such as the inability to communicate, make decisions, recognize family members, or remember information for more than one minute at a time. Struggles with pain may cloud thinking. Uncertainty or awkwardness with compensatory strategies or cognitive decline such as in executive functions may contribute to social withdrawal. Difficulty Fear about the immediate, serious nature of the injury as well as long-term consequences and unknowns about future abilities to function build up stress. 10 As essential as the physician and other health professionals are to treatments and healing, the patient, assisted by supporting family, should be empowered as much as possible to have a role as a key leader of the healing team. 12 In the medical evaluation, discussion of possible treatments, and design of the treatment plans, the patient is key and therefore should be involved whenever possible and appropriate in the discussion of clinical findings, needed tests, treatment choices, and care plan decisions.

The patient's success toward recovery depends greatly on the health team working with high levels of respect and professionalism that demonstrate to the patient and family support person(s) cultural sensitivity and competence, building of trust, fostering of hope during challenges and adaptations, ongoing clear communication, and honesty. Thus, the patient in partnership with others on the health team may become strongly invested in and regain a sense of control regarding therapy decisions. b) Caring for the Family Support Person 13,14 The family support person for someone who has had a TBI usually is a close family member, partner, or friend with deep emotional ties. Suddenly the family support person faces multiple responsibilities, not only survival-dependent medical decisions of the injured loved one, family matters such as paying bills, keeping up with the schedule of other family members, providing transportation, meals and other duties which the person with the TBI previously managed. Depending upon the nature of the TBI, the family support person may be on call 24/7 for the medical team in case of a sudden change in the patient's status. Additionally the family support person must balance the independent/dependent-interdependent functioning and changes of the person with the TBI. Not knowing the quality or the timeline of the recovery, difficulties communicating with the person who has the TBI as well as diverse health and social service providers may lead to overwhelming physical, emotional, and socioeconomic stress. Neglected caregiver stress may lead eventually to burnout with the family support person feeling intensely overwhelmed and no longer able to keep up with the constant demands of care management. This downturn in support may set up risks for neglect or abuse of the person with the TBI.

Effective coping involves a focus on the problem and the steps (even small steps) towards recovery and learning to manage the stress of caregiving. Books, support groups, and experts such as psychologists, mental health counselors, clergy, and social workers can help the family support person learn coping strategies such as identifying help from community services, volunteers, or part-time, paid helpers to provide transportation, meals, homemaking tasks, etc.

Important to caregiver coping is learning how to take time for rest to refresh oneself, to follow a daily healthy lifestyle including good nutrition, adequate sleep, time for exercise and pleasant activities such as listening to music, watching a comedy, reading an enjoyable book, time with pleasant friends or alone time, and regular respite, brief periods of separation such as 10 minutes daily to refresh oneself or longer periods such as a weekend once a month or more often.

2 c) Early Referral

Not only do the patient, supportive family, and physician have to trust, respect, and communicate clearly with each other, but early on it is also essential to the recovery process to access a diverse network of health providers

and resources to arrange a comprehensive approach to recovery to begin as soon as possible. Sometimes TBI injuries involve impaired: memory, communication, thinking, vision, hearing, balance and movement, skilled hand movements, orientation to time or place, etc. These sometimes obscure disorders may lead to chronic stress, anxiety, and depression. Untreated stress, anxiety, and depression may magnify the impact of the brain dysfunctions directly related to the injuries from the TBI incident.

Healing should entail input from other health and social service experts. As soon as possible, referrals should be made to speech and hearing, physical therapists, occupational therapists, neuropsychologists, mental health counselors, neurologists, dentists, social workers, etc. for full evaluations and treatment recommendations. Delay in referrals may lead to high levels of frustration. For example, the patient who struggles with hearing, understanding, speaking, or other language issues may misinterpret complex directions. Memory problems may result in poor recall of important details of care. The patient with TBI to the right hemisphere may misunderstand or miss completely the emotion underlying the body language (kinesics) or speech of be masked and missed; if left untended, they may build frustration, anger, stress, anxiety and depression in the patient as well as the family support person and thus derail the progress toward recovery. d) A Care Notebook One of the first and most useful strategies is to start a Care Notebook, a tool to help manage sundry details. Similar to a journal, a Care Notebook is an important resource for the person with TBI as well as the family support person. A Care Notebook should be started as soon as possible after the traumatic event (even from the beginning moments when the person suffering with the TBI first receives medical attention) as it may help to record the details of what initially occurred. When appropriate, the Care Notebook should become the responsibility of the person with the TBI.

Keeping regular notes in this Care Notebook will help update both the person with TBI and the family about the different people, tests, treatments, and appointments that are involved in the daily care management and recovery process. The Care Notebook provides a place for a To-Do-List, with a check, date and special comments after completing a task; a record of health team members and their roles; a list of medicines and dosage; a schedule of therapies, etc. After the traumatic brain injury event, the focus of immediate (and early) care is likely to involve many emergency procedures.

Once stabilized with emergency care, the patient and family can start to review and note the way to move forward and the overall approach with the health team. Moving forward may involve several steps and care goals. At this time keeping a record of vital information in the Care Notebook will help to keep the steps and people involved clear about the sequence of directions for moving forward. A review of previous notes can point out progress. A different format for a Care Page that tracks medicines can keep the patient, family and health team updated, especially as dosage and frequency change and which medicines were tolerated well versus those with unpleasant side effects. [See an example of such a page (Figure 2. Care Page Example #2) at the end of this article]. The person with the TBI may not be able to participate fully in the early stages of healing; therefore, family and significant others may help by noting initially on the care pages for medicines any valuable information such as comments about allergies and sensitivities to medicines (and foods). Changes in medicines during the course of healing, especially when the person is taking different medicines, are often challenging depending upon the complexity of injuries and individual differences. Sometimes when the person is taking several medicines, changing one medicine may affect how the other medicines work, such as the interaction leading to a stronger or weaker effect of a drug or side effects such as nausea, vomiting, or dizziness. Tapering off a former medicine and building up the dosage of the new medicine may lead to unexpected temporary inadequate levels of therapy or toxicity due to intolerance of the additional new medicine. Tolerance of a new medicine may fluctuate abruptly due to a sudden status change such as decreased kidney or liver function or an incipient infection. Thus, a Care Page for medicines can keep the patient, family and health team members updated and readily responsive to apply needed interventions.

3 f) Memory Strategies

Among the various cognitive dysfunctions that may follow a TBI, short-term memory difficulties may provide a major hindrance to adaptation and recovery. When a TBI disrupts memory function, stress from the medical setting amplifies the difficulty keeping track of cumbersome details, therapy appointments, the self-care schedule, and the names and contact information of staff.

i. For the person with TBI 1. In addition to a Care Notebook, use a small, pocket-size or purse-size "memory notebook" with bound pages (not a loose leaf notebook) to write down important details, such as the daily schedule of health care and other tasks to do, appointments, people to phone, items to buy, etc., and check off what has been done. Keeping these details in a small notebook will serve as reminders about the schedule of tasks, etc. Then check off when tasks are done, visits completed, brief notes, etc. As an alternative, dictating into an iPod with a reminder alarm may help (iPhone and iPad apps convert speech to text, for example Dragon, speech to text).

2. As questions come up during the day, record the questions and answers which can be referred to later. 3. When thinking of a detail to tell someone, write it down (or dictate it) and then check it off when it is completed.

5. Express words of appreciation for reminders and help; remember the magic words "Please" and "Thank you". 6. Use Google to help with the word finding process. 7. Use yellow paper, post-it notes or different colored

post-it notes for different topics. Or, try post-it notes, already installed on most computers, to make it easy to write down reminders daily on a to-do list.

There are also useful health and disability Apps, which may help. See the following list of suggestions:

(at Disabled World: Health and Disability Apps for iPhone Android and Mobile Devices, see <http://www.disabled-world.com/assistivedevices/apps/>) ii. For the physician and other health/social service professionals 1. Repeat simple details in simple sentences. 2. Plan for enough time for the questions and concerns of the patient and family members to be addressed by different staff such as a nurse, social worker, health aide, physical therapist, occupational therapist, speech therapist, dentist, financial counselor, etc. 3. Give information and directions orally, in written form, and on a tape or CD. As an alternative, give directions in pictures. 4. Give simple choices such as one or two choices as a way to respect the patient and then remind the patient, for example, "As you just decided, we are going to start physical therapy first. Then medicine A to see how it works. What do you think of this plan?" 5. Express words of appreciation for opinions and help from the patient and family; remember the magic words "Please" and "Thank you".

4 g) Communication Strategies

Critical to careful and safe healing is clear communication to and from: the patient, family support person, and health and social service providers. Any questions or doubts about a procedure, medicine or health staff should be acknowledged as being heard, evaluated, and followed-up. To facilitate communication, it may be useful: i. For the person with TBI 1. Think about questions (and concerns) ahead of a medical visit or appointment, write them down, dictate them into an iPhone or other tech device.

When staying in a hospital or rehab center, put the questions on the hospital bedside table so the incoming doctor or nurse will see and respond to the questions quickly. 2. Email a list of concerns and questions ahead of time to the doctor's office to allow the medical staff time to look up information and answers before the time of the medical appointment. 3. Write down words when speaking is difficult. Try to use hand gestures, point to pictures, or draw pictures to show what you want or are thinking. 4. Request help from a family member to explain your concerns to the medical staff.

ii. For the physician and other health/social service professionals 1. Listen carefully to words and watch body language such as facial expressions to learn about the obvious message and the subtle or hidden message. 2. Print instructions in large, bold, simple font, such as 16 point Arial. 3. Use pictured instructions such as pictures of exercises or a picture of a calendar highlighting the date of the next appointment with a clock pointing to the appointment time. 4. Ask simple questions that easily lead a patient to answer with a spoken "yes" (or nodding the head up and down or one eye blink) or a spoken "no" (or shaking the head side to side or two eye blinks). Alternatively, a patient may raise a finger or hand or leg to show yes or no answers. 5. If hand and finger skills function well, refer the patient to a speech therapist to teach about alternative communication using computer icons or Amerind (American Indian Sign Language, a language of gestures, www.inquiry.net/outdoor/native/sign.htm). 6. Show a group of simple smiley faces to ask about feelings, pain, or mood: Long periods of time may be necessary for healing; sometimes years pass before maximum medical improvement is achieved. When the recovery process has taken place and when the patient is ready to enjoy socialization, close friends may have moved on to different responsibilities, interests, and locations. As a result, the patient who has the TBI may feel disconnected or even isolated, despite the best efforts of family members. Working together, the patient, different health professionals, family members, and community resources such as support groups (offered by the Brain Injury Association) should help to address the challenges and set-backs the patient will encounter. Such an approach with the health team and reminders to the patient and family support person that the healing process is a long term process should help to address the hurdles and impatience that typically surface in the extensive, long-term work towards successful healing. In time and with guidance from a support network, the person with the TBI may find parttime employment, a different type of employment, volunteer work, or, as a motivational speaker or writer, shares lessons learned during the recovery. A collaborative approach and creative thinking should develop steps toward optimal adaptation in a positive, fulfilling direction.

5 II.

6 SUMMARY

Each day, almost 140 people in the United States die from injuries that include TBI. Their recovery may take a few days, several years, and may result in lasting disabilities (http://www.cdc.gov/traumaticbraininjury/get_the_facts.html). To optimize healing and rehabilitation, the patient should be respected as a key member of the health team and the patient-family/physician relationships should be strong. The person with TBI as well as the family support person, need help, support, and respite over the long-term course toward recovery. The early intervention of various health professionals with support from extended family, community programs and links to e-resources are essential to help in the long-term healing and adaptations necessary for the person with TBI to become as self-sufficient and re-integrated as fully as possible into family and community life. .



Figure 1:



Figure 2:

Medicines

Allergies & Sensitivities:

Describe reactions & treatment:

Date: Month/Day/Year

Medicine Dose/Route

Circle how often taken

Aspirin 325 mg. tablet by mouth

1Xdaily 2Xdaily 3Xdaily 4Xdaily bed time if
needed

Medicine XX

1Xdaily 2Xdaily 3Xdaily 4Xdaily bed time if
needed

Medicine YY

1Xdaily 2Xdaily 3Xdaily 4Xdaily bed time if
needed

Medicine ZZ

1Xdaily 2Xdaily 3Xdaily 4Xdaily bed time if
needed

Figure 3:

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