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Disability Burden In Traumatic Brain Injury
In Gaza Strip

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بِسْمِ اللّٰهِ الرَّحْمٰنِ الرَّحِیْمِ



یوسف 101

صَدَقَ اللّٰهُ الْعَظِیْمَ

ABSTRACT

OBJECTIVE: The purpose of this study is to determine the burden of disability of traumatic brain injury (**TBI**) individuals on caregivers after discharge from rehabilitation hospital from the caregivers' perspectives in the Gaza Strip. **RESEARCH DESIGN:** The researcher used an analytic descriptive structure in order to perform the study. **METHODS:** The study sample comprised all **TBI** individuals who were hospitalized between January 2000 and January 2007 in El Wafa Medical Rehabilitation Hospital and Specialized Surgery. Convenience sampling strategy was used. **SETTING:** The study was conducted in the Gaza Strip: Northern of Gaza, Gaza City, Middle Zone, Khanyounis and Rafah. **PARTICIPANTS:** Respondents included One hundred of **TBI** caregivers who had at least 6 months experience as **TBI** caregivers. Respondents ranged in age from 18 to 49 years whom had been visited at their homes. **OUTCOMES MEASURES:** Functional Independence Measurement (FIM), Disability Rating Scale (DRS) and Community Integration Questionnaire (CIQ). **RESULTS:** The average score of **TBI** caregivers in the CIQ was found to be 15.3/ 29 (52.8%). The average score of the FIM for **TBI** individuals was calculated at 80.7/126 (64%). Psychosocial adaptability in terms of employability established the most important item in DRS for participants **TBI** individuals 2.1/29 (7.2%) while dependency on other (level of functioning = 1.7/29 (5.9%)) came in the second place. Cognitive and awareness abilities were in the third and fourth place according to DRS (5.5%, 3.4%). **CONCLUSIONS:** Participants in the study reported high level of disability burden after they provided care to **TBI** individuals and lower of community integration in the society (52.8%) due to caring **TBI** individuals.

ABSTRACT IN ARABIC

2000
2007
()
/
49-18
15.3/ 29 :
(64%) 126/ 80.7 .%52.8
(7.2%) 2.1/29
(1.7/29 (5.9%))
(3.4% , 5.5%)
:
%52.8

DEDICATION

I would like to take this opportunity to express my deepest thanks and dedicate this work for my dear parents for their continuous support along the way, for my brothers and sisters, for Raged my sister kid and for the memory of my grand mother.

Also I would like to dedicate this thesis to all my family, my dear friends and for all the lovely people that I know.

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The researcher thanks God for infinite godsend. She would like to thank her study leaders, Dr. Ziad Al -hawamdeh and Dr. Atef Al-Agha, for their constant endeavors, supervision and assistance. She also acknowledges the cooperation of the participants in the study, TBI individuals and caregivers, many thanks for their valuable time and information. The work completed by research assistants was of great importance to bring this project to reality, million thanks. The researcher would like to express her sincere gratitude to El Wafa Rehabilitation Hospital, Dr. Khamiss El - Essy, Dr. Fadel Naeem, Mr. Moussa Abu Mostafa and Mr. Ghanem Miqati for their never-ending support and encouragement during the whole process of the thesis writing. The researcher also sends her sincere gratitude to the committee of examiners for their advices and comments. She would like to thank all the members of the faculty of Education in the Islamic university of Gaza, colleagues and friends for their support and recommendations.

DECLARATION

I certify that this thesis submitted for the degree of master is the result of my own research, except where otherwise acknowledged, and that this thesis (or part of the same) has not been submitted for a higher degree to any other university or institution.

Signature

Amani

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ACRONYMS

ABI	Acquired Brain Injury.
CDC	Center for Disease Control and prevention.
CIQ	Community Integration Questionnaire.
CNS	Central Nervous System.
CSF	CerebroSpinal Fluid.
DRS	Disability Rating Scale.
FIM	Functional Independence Measures.
GCS	Glasgow Coma Scale.
PNS	Peripheral Nervous System.
TBI	Traumatic Brain Injury.

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CHAPTER "1"

INTRODUCTION

AND

IDEA INITIATED STUDY

- 1.1 Introduction**
- 1.2 Idea initiated the study**
- 1.3 Aims of study**
- 1.4 Objectives of study**
- 1.5 Research questions**
- 1.6 Terminology:**
 - 1.6.1 Traumatic Brain Injury*
 - 1.6.2 Caregivers*
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 - 1.6.7 Social Impact Of Traumatic Brain Injury*
- 1.7 Operational definitions**
- 1.8 Study domains**
- 1.9 Summary**



1.1 Introduction:

In the Name of Allah, the Most beneficent, the Most Merciful,

All the praises and thanks be to Allah, the Lord of Alamin (mankind, jinns and all the exists), and Salam (peace) and Salat (Blessings of Allah) be upon the last (end) of Allah's Profets and Messengers, Muhammad Ibn Abdullah (صلى الله عليه و سلم), the trustworthy to whom was revealed the Devine Inspiration (the Qur'an and Sunna) in the plain Arabic language.

Allah, the Most High, said: "Read! In the Name of your Lord, Who has created (all that exists) {1}, Has created man from a clot (a piece of thick coagulated blood) {2}, Read! And your Lord is the Most Generous {3}, Who has taught (the writing), by the pen [the first person to write was Prophet Idrees (Enoch)] {4}, Has taught man that which he knew not {5}" [Surat Al-Alaq, Sections: 1-5]

On the authority of Abu Hurairah "radiAllaahu anhu" that the Prophet (sallAllaahu alayhi wa sallam) said: "And whoever follows a path to seek knowledge therein, Allaah will make easy for him a path to Paradise". It was related by Muslim in these words. And in this hadeeth is mentioned the virtue of fulfilling the needs of a Muslim, and of striving in the Path of seeking Knowledge, and this includes the virtue of being pre-occupied with Knowledge. And what is intended by Knowledge here is the Knowledge of the Sharee'ah. And all this requires that one intends by it the Face of Allaah ta'aalaa, just as this is a condition in every act of worship.

On the authority of Ameer ul-Mu'mineen (the Commander of the Faithful), Aboo Hafs `Umar ibn al-Khattaab radiAllaahu anhu, who said: I heard the Messenger of Allaah sallAllaahu alayhi wa sallam says: "Actions are but by intentions and every man shall have only that which he intended. Thus he whose migration (Hijrah to Madeenah from Makkah) was for Allaah and His Messenger, his migration was for Allaah and His Messenger, and he whose migration was to achieve some worldly benefit or to take some woman in marriage, his migration was for that for which he migrated." It is related by the two Imaams of the scholars of Hadeeth.

Everything we do has to be intended to be for Allaah, for example, for anything we do we want to make sure that it will be acceptable to Him and will not in any way interfere with the upholding of His Deen. A good action with the wrong intention will not get us any reward in the Hereafter. The researcher, with this study, entirely seeks the sake of Allah, Glory be to Him, looking for Akherah (End) reward that is Jannat ElFerdaws with Prophets and Martyrs.

Traumatic brain injury (**TBI**), according to Middleton and Lloyd (2002), is a challenging disorder of body and mind which occurs due to brain assault or external physical attack. **TBI** is different from degenerative and congenital brain lesions in that **TBI** is caused by trauma to the head including the effects upon the brain or other possible complications of injury (Campbell, 2000). **TBI** has various demanding aspects such as acute management, recovery, rehabilitation, complications and disability burden. **TBI** may lead to long term behavioral, cognitive, physical, mental, social deficits which might influence daily activities of patient and caregiver.

Escalating violence and ongoing conflicts and wars in the developing countries make trauma in general and traumatic brain injury (**TBI**) in specific leading causes for death and disability in these countries. The impact of **TBI** on survivors and, therefore, the needs of patients go beyond the provided services within hospitalization, institutional and community rehabilitation. Caregivers at home or community situations post-discharge are obliged to replace professional and well-trained rehabilitation team which may restricts their performance in various daily activities and social roles.

Past research in the 1980s addressed the recovery from physical and cognitive symptoms in **TBI** survivors such as Oddy, et al. (1985). More recent research in the 1990s investigated **TBI** in childhood, complications and resuming former capacities such as Dikmen, et. al, (1993) and Acorn (1993).

New studies in 2000s investigated family needs change over time (Kolakowsky-Hayner, et al; 2001). New arena in research evaluated economic and social consequences of **TBI** across lifespan (Serna & Sousa; 2006). Most recent studies in 2007 focused on disability burden, caregivers' perspectives, such as stress, depression, emotional and cognitive disturbances (Rivera, et al; 2007).

This study is a complementary endeavor. The researcher will investigate the area of disability burden on caregivers from another perspective; influence of disability burden on caregivers' social interaction, community participation and performance in activities of daily living.

According to Smith (2005), **TBI** during childhood constitute a major medical and public health problem. Approximately 4.000 children die each year of head injuries in the United States (CDC; 2006) *. Estimates by the National Institute of Health; (2004) Consensus Development Panel on Rehabilitation of Persons with **TBI** showed that 2.5-6.5 million Americans live with **TBI**-related disabilities.

The study will be conducted in the Gaza Strip, Occupied Palestinian Territories which is an underdeveloped country. The people in the Gaza Strip live in very difficult humanitarian circumstances of internal conflicts and violence, Israeli occupation, poverty, poor sanitation and political situation, and closure of borders/embargo. This situation started in 1930s – 1940s. The result is thousands and thousands of victims and unfulfilled increasing needs.

The researcher started to investigate the present topic "Disability burden in **TBI**" in 2006 and followed up the ongoing relevant research and she reviewed past research as well. Up to date, this is the first study to be conducted in the Gaza Strip about disability burden in **TBI**. The researcher think that the impact of **TBI** may extend beyond the hospitalization, institutional, community and rehabilitation needs of the disability. Moreover, she links between brain injured patient as a person with special needs and challenges and different life situations of a caregiver such as social roles, work, shopping and leisure activities. Caregivers might demonstrate unwelcome changes in these life situations such as poor care of other children and limited free time activities which is a worthwhile area for research. The researcher in the current study is intending to identify the influence of disability burden of **TBI** patients on their caregivers' social interaction, productivity and performance in activities of daily living.

In addition, the researcher aims to provide something to an important category of those needy people, occupationally deprived and marginalized **TBI** patients, to alleviate there intolerable suffering. Moreover, the researcher aims to find new strategy that might reduce disability burden on **TBI** patients and their caregivers.

* Center for Disease Control and prevention (CDC): an annual report, the main goal, to promote health and quality of life by preventing and controlling disease, injury, and disability. Healthy People in a Healthy World—Through Prevention.

1.2 Idea initiated the study:

Trauma is a leading cause of death and disability according to Center for Disease Control and prevention (CDC; 2006). Middleton and Lloyd (2002) defined **TBI** as brain injury from externally inflicted trauma and it may result in significant impairment of an individual's physical, cognitive and psychosocial functioning.

The same authors (Middleton and Lloyd) added that **TBI** affects people of all ages and it is the leading cause of long-term disability among children and young adults. Traumatic brain injury is likely to affect families in different ways, especially given the marked risk of ongoing neuropsychological, behavioral, and academic problems in these children. According to Millis, et. al, (2001) caregivers of patients who have experienced **TBI** have reported elevated levels of burden and depression. Moreover, caregiver distress has been shown to increase with time since the injury (Douglas & Spellacy, 1996; Kreutzer et al.; 1992). Literature search revealed that there are few studies which investigated the effect of **TBI** on caregivers such as Douglas and Spellacy (1996), Kreutzer et al; (1992).

1.3 Aims of study:

The present study brings **TBI** patients and caregivers into focus of research in the Gaza Strip. It investigates the main concerns and challenges facing caregivers of **TBI** patients. **TBI** patients and their caregivers can simultaneously suggest appropriate solutions to their problems from their perspectives. This participates in **TBI** patients and caregivers empowerment.

Health policy decision makers will recognize and are more likely to address the real needs, drawn from the study findings, of **TBI** patients and their caregivers. Meeting real needs might require vertical and horizontal development of delivered services to **TBI** patients and their caregivers. This can be translated to more training on **TBI** rehabilitation, new specialized rehabilitation centers and new health promotion projects.

Study finding, therefore, should encourage new health project in the Gaza Strip. These projects can be related to providing essential disposable materials, assistive aids, disability bench, implementing disability rules such as "Work Act" and environmental adaptation.

During data collection, the researcher and the research assistants are going to visit out of reach individuals and marginalized areas. These areas are near the borders and not safe at all.

The study findings should enhance responsible organizations, governmental, non-governmental and international, to improve provided health services and advocate these individuals' rights.

The study is going to address strength, weakness, opportunities and threats in **TBI** caregivers' community integration. It should predict the influence of caring a disabled patient with **TBI** disorder on life situations such as caring children, shopping, and visiting friends and relatives. The study findings should be useful to alleviate disability burden and enhance caregivers' community integration through suggesting solutions that relieve caregivers' problems.

Because of the high incidence of **TBI** in childhood and young adulthood, and the long-term impact of **TBI** on employment, **TBI**-related disability has enormous economic and social consequences across the lifespan (Serna & Sousa; 2006). Therefore, the current study may suggest solutions that decrease the total expenses of **TBI** rehabilitation and community integration.

The current study is a new addition to rehabilitation and physiotherapy literature. Moreover, it may establish opportunity for further research in the area of **TBI**, disability burden and community integration. The study can be replicated for comparison in different populations such as Spinal Cord Injury patients, different countries such as Egypt and Jordan and different circumstances such as occupation-free country taking in account to avoid shortcomings.

The researcher in the present study is going to use standardized data collection instruments: Community Integration Questionnaire (CIQ), Functional Independence Measures (FIM) and Disability Rating Scale (DRS). In order to use these scales in the Gaza Strip which is an Arabic community, the researcher will translate them into Arabic. In addition, the researcher is going to measure the validity and reliability of the translated scales. This will produce an Arabic version of the employed scales; CIQ, FIM and DRS.

Ewles and Simneth (2003) stated that health promotion refers to raising the health status of individuals and communities. Health promotion has two fundamental

elements: improving health and having more control over it. Based on this definition, the current study participates in community health promotion.

1.4 Objectives of study:

The present study has four objectives and they are as follow:

1. To measure the performance of **TBI** patients according to the Functional Independence measurement (FIM);
2. To assess the degree of disability of **TBI** patients according to Disability Rating Scale (DRS);
3. To evaluate the **TBI** caregivers' integration according to Community Integration Questionnaire (CIQ),and
4. To determine the burden of disability of traumatic brain injury patient's on caregivers after discharge from rehabilitation hospital from the caregivers' perspectives.

1.5 Research questions:

The study addresses four questions which investigate the **TBI** patients' performance and **TBI** caregivers' perspectives after discharge from rehabilitation hospital with a minimum period of 6 months.

1. What is the performance level of **TBI** patients according to functional independence measurement (FIM)?
2. What is the degree of disability of **TBI** patients according to disability rating scale (DRS)?
3. What is the degree of integration of **TBI** caregivers according to community integration questionnaire (CIQ)?
4. What is the burden of disability of traumatic brain injury patient's on caregivers after discharge from rehabilitation hospital from caregivers' perspectives?

1.6 Terminology:

The researcher, in the present study, used various terms such as traumatic brain injury, disability, caregiver and rehabilitation. These terms will be illustrated in the following subchapters.

1.6.1 Traumatic Brain Injury:

Randall and Braddom (2000) defined **TBI** is as a result of physiological disruption of normal brain function, such as trauma from either external (an object

striking the head or the head striking an object) or internal events (the rapid acceleration/deceleration of the brain within the cranial vault) or both.

This definition was developed from head injury to traumatic brain injury and it's clearly denotes that injury to the brain is the major cause of morbidity and mortality and that the injury caused by external force.

1.6.2 Caregivers:

Caregivers provide assistance to other people who because of physical disability, chronic illness or cognitive impairment are unable to perform certain activities on their own. **Informal care** can be offered by family members or friends, often in a home setting. or paid or volunteer professional care. **Formal care** can be obtained at home, in the community or from institutions such as nursing facilities or government institutions (Seaback, 2001).

1.6.3 Disability:

International classification of functioning, disability and health (ICIDH II; 1999); defines disability as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

1.6.4 Burden Of Traumatic Brain Injury:

Families of people with **TBI** face numerous challenges and stresses in providing care. They face living with and providing care for a person that in many ways is different from the person he or she was before the injury. The injured family member may demonstrate a variety of physical and behavioral care needs that make family caregiving especially stressful and burdensome. As families have been increasingly recognized as the primary caregivers for people with **TBI**, varied research has investigated the extent of stress and burden family caregivers experience. In fact, this focus has dominated **TBI** caregiver research over other important caregiving factors, such as coping strategies family caregivers use (Kosciulek; 1994).

1.6.5 Depression:

Depression is defined as an emotional problem that has physical, thinking, and mood components. Symptoms can include feelings of sadness, anger, apathy, and irritability that are present for a period longer than two weeks. Anxiety can be associated with

depression as well. People who are depressed have characteristic ways of thinking such as hopelessness, negativism about themselves or the future, inability to generate options, reduced attention and concentration, and forgetfulness, to name a few. Typical features of depression are thoughts of life's futility, which can lead to thoughts of suicide. There are specific physical symptoms of depression that include fluctuations in appetite, weight loss or gain, sleep disturbance, fatigue, general malaise, pain problems, and decreased interest in sex. These are serious symptoms and if they persist, generally require treatment such as counseling, and in more serious cases, medication (Donald and Wender; 2005).

1.6.6 Rehabilitation Of Traumatic Brain Injury:

The goal of rehabilitation is to help **TBI** patients and to reach the independent level as much as possible. Rehabilitation helps the body heal and assists the brain in relearning processes so that an individual recovers as quickly and efficiently as possible. The person with **TBI** and his or her family are the most important members of the rehabilitation team. Family members should be included in the rehabilitation and treatment as much as possible. It is important to remember that rehabilitation may last years and that **TBI** will benefit from the ability to receive rehabilitation services throughout this time. Appropriate programs and treatments will also change as the family member's needs change (Stokes, 2004).

1.6.7 Social Impact Of Traumatic Brain Injury:

Campbell (2000) discussed the impact of **TBI** patients on their caregivers (social aspects), not all families make it through this five stages process and not all families members are able to progress at the same speed. Both **TBI** survivors and their family members faced new challenges when the survivor returned home from the hospital. Often, interactions between the survivor and family became tense because **TBI** brought multiple internal and external pressures to all family members. Those pressures gradually wore down the survivor's confidence and eventually led him or her to feel abnormal. In turn, the survivor increasingly behaved in ways that fell outside family and social norms. Mothers' uncertainty when interacting with a child's sense of abnormality induced more strain on the mother-child relationship. Mothers of **TBI** survivors reported they struggled with conflicting desires between encouraging dependence and

allowing autonomy for their injured children. Mothers struggled to rebuild a harmonious life and evaluated their marital relationships.

1.7 Operational definition:

1.7.1 Traumatic brain injury (TBI):

Traumatic brain injury is a devastating lesion. It happens due to external physical attack such as; road traffic accidents, falling down, gunshot and explosive injury. May it sustains a permanent impairment which results in neurological signs such as weakness of one side or both sides of the body, inability to properly perform in communication, walking and daily activities. Moreover, vital abilities for well-functioning might be affected such as memory, attention and ability to solve problems. Therefore, rehabilitation is crucial and it intervenes to help **TBI** individuals regains lost abilities and performs activities of daily living independently as much as possible. The performance level of **TBI** measured by functional independence measurement (FIM).

1.7.2 Traumatic brain injury caregivers:

An individual who provides assistance in activities of daily living for a **TBI** individual. **TBI** caregivers are primary or secondary. Primary caregiver is providing the most necessary assistance in daily activities needed by **TBI** individuals while secondary caregivers support and help primary caregivers.

1.7.3 Burden of TBI caregivers:

Caregivers of **TBI** individuals may suffer a variety of psychosocial effects, including post-traumatic stress disorder, depression, and social lives. This burden can measured by community integration questionnaire the lowered scores mean less integration in the society. The burden may includes economic effects, when the **TBI** individual needs increase by time if the disability severe such as; medical coast of treatment. The degree of disability of **TBI** patients can measured by Disability Rating Scale (DRS) and after that the burden can measured by integration of caregivers in the society by community integration questionnaire (CIQ).

1.8 Study domains:

The study is defined by four main domains: place, time, people and items of study.

- **Place:** The study will be conducted in the Gaza Strip: Northern of Gaza, Gaza City, Middle Zone, Khanyounis and Rafah.
- **Time:** The fieldwork – data collection – is going to take place between July 1st and August 1st 2007.
- **Sample/People:** The study population is all **TBI** individual caregivers in the Gaza Strip who were discharged from "El Wafa Rehabilitation Hospital and Specialized Surgery" in the period 2000-2007.
- **Study instrument items:** The current study is addressing 15 items of disability burden from caregivers' perspectives such as shopping, household, caring for children, leisure activities and productivity.

1.9 Summary:

A lot have been done for traumatic brain injury in terms of prevention, acute and subacute management and rehabilitation; however, **TBI** is a leading cause of death and disability among a fundamental and huge population category that is children and adults. An important area needs special concern in the Gaza Strip is **TBI** burden during inclusion and residency in the community. Generally, research focused on **TBI** survivors while didn't pay attention to the possible suffer and deprivation of caregivers of **TBI** individuals. In this study, the researcher aims to provide something to this category to alleviate their potential suffering. Moreover, the researcher aims to set a strategy that might, in case, reduce disability burden of **TBI** on their caregivers.

The researcher will discuss the used literature in chapter two and summarize the most important and relevant research to the current study topic in the chapter three. In chapter four the researcher is going to explain the used methodology such as study design and sampling strategy. The study results and important findings will be presented in chapter five; in which the researcher is going to use tables and charts. Chapter six will focus on the study findings discussion, conclusions and recommendations.

CHAPTER "2"

CONCEPTUAL FRAME WORK

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2.1 Introduction:

Traumatic brain injury (**TBI**) also called intracranial injury and it occurs when a sudden trauma causes brain damage. **TBI** can result from a closed head injury or a penetrating head injury and is one of two subsets of acquired brain injury (**ABI**). The other subset is non-traumatic brain injury (e.g. stroke, meningitis, and anoxia). Parts of the brain that can be damaged include the cerebral hemisphere, cerebellum, and brain stem. Outcome can be anything from complete recovery to permanent disability or death (Waxman; 2002).

The researcher, in chapter two, will illustrate the theoretical framework of study. **TBI** definition is will be made clear and distinguishable from other diagnosis in terms of pathophysiology, types and complication. **TBI** management takes place in acute care, rehabilitation phase and community situation. Caregivers are involved in **TBI** management and their roles, duties. Therefore their social participation and performance in daily activities differ accordingly (Campbell; 2000).

2.2 Brain anatomy:

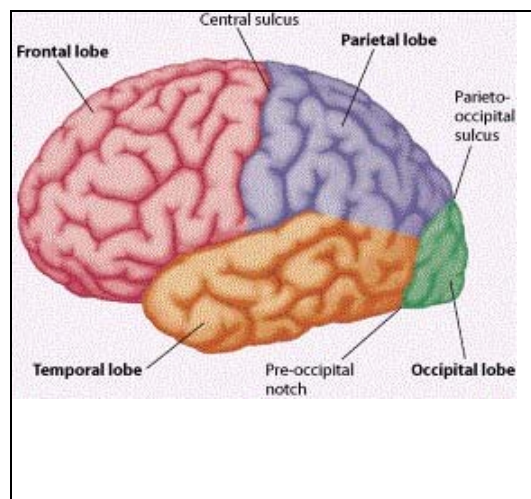


Figure 1. Brain anatomy

The human brain is the most complex organ in the human body. It contains some one hundred billion neurons that receive, analyze, and store information about internal and external conditions. It is also the source of conscious and unconscious thoughts,

moods, and emotions. The brain, though representing 2% of the total body weight, it receives one fifth of the resting cardiac output. The brain and spinal cord make up the central nervous system. The spinal cord attaches to the brain through a hole at the base of the skull (Foramen Magnum). The skull base forms the floor of the cranial cavity. This anatomic region is complex. The bones that make up the skull base are the ethmoid, sphenoid, occipital, paired frontal, and paired parietal bones. The skull base can be subdivided into three regions: the anterior, middle, and posterior cranial fossa. The petro-occipital fissure subdivides the middle cranial fossa into central component and lateral components. This blood supply is carried by the two internal carotid arteries (ICA) and the two vertebral arteries that anastomose at the base of the brain to form the circle of Willis. Carotid arteries and their branches (referred to as the anterior circulation) supply the anterior portion of the brain while the vertebrobasilar system (referred to as posterior circulation) supplies the posterior portion of the brain (Rowland; 2005).

Four major brain divisions govern its main functions: the cerebrum, the diencephalon, the cerebellum, and the brain stem (Waxman; 2002).

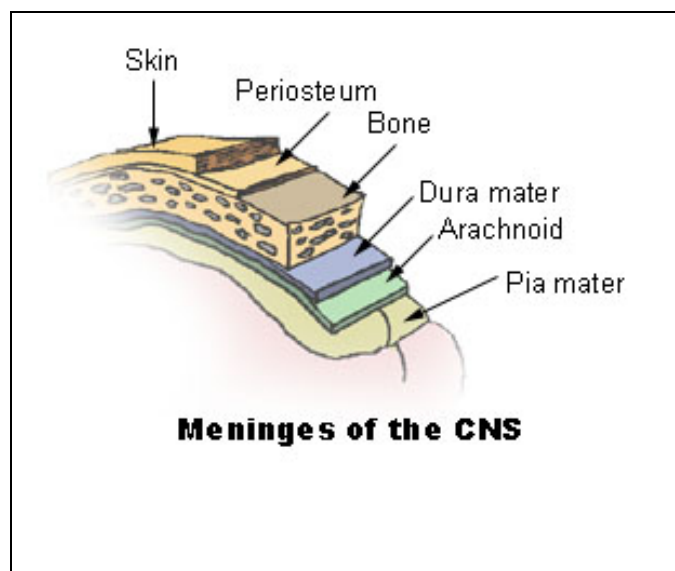


Figure 2. Meninges of CNS

The **meninges** consist of three layers: dura mater, arachnoid mater, and pia mater. The primary functions of the meninges and is to protect the central nervous

system. The **pia mater** is a very thin membrane composed of fibrous tissue covered on its outer surface by a sheet of flat cells thought to be impermeable to fluid. It's attached to (nearest) the brain or the spinal cord. The pia mater is pierced by blood vessels which travel to the brain and spinal cord, and its capillaries are responsible for nourishing the brain. The pia mater is the meningeal envelope which firmly adheres to the surface of the brain and spinal cord and it is a very delicate membrane. The middle element of the meninges is the **arachnoid mater**, also named because of its spider web-like appearance. The arachnoid mater exists as a thin, transparent membrane. It provides a cushioning effect for the central nervous system. It is composed of fibrous tissue and, like the pia mater, is covered by flat cells also thought to be impermeable to fluid. The arachnoid does not follow the convolutions of the surface of the brain and so looks like a loosely fitting sac. In the region of the brain, particularly, a large number of fine filaments called arachnoid trabeculae pass from the arachnoid through the **subarachnoid** space to blend with the tissue of the pia matter. The subarachnoid space is the space which normally exists between the arachnoid and the pia mater, which is filled with cerebrospinal fluid. The dura mater is a thick, durable membrane, closest to the skull. It contains larger blood vessels which split into the capillaries in the pia mater. It is composed of dense fibrous tissue, and its inner surface is covered by flattened cells like those present on the surfaces of the pia mater and arachnoid. The dura mater is a sac which envelops the arachnoid and has been modified to serve several functions. The dura mater surrounds and supports the large venous channels (dural sinuses) carrying blood from the brain toward the heart (Waxman; 2002).

Cerebrospinal fluid (CSF) is a clear bodily fluid that occupies the subarachnoid space and the ventricular system around and inside the brain. It is an approximately isotonic solution and acts as a "cushion" or buffer for the cortex, providing also a basic mechanical and immunological protection to the brain inside the skull. The amount is produced at a rate of 500 ml/day. Since the brain can only contain 150 ml, large amounts are drained primarily into the blood. CSF contains approximately 0.3% plasma proteins, or 15 to 40 mg/dL, depending on sampling site. CSF has many assumed roles including mechanical protection of the brain, distribution of neuroendocrine factors and prevention of brain ischemia (Barbra and Grieve; 1996).

The central nervous system (CNS) consists from the brain and spinal cord. the connecting nerve processes to effectors and receptors serve as the peripheral nervous system (PNS).

The cerebrum is the large rounded area that divides into left and right hemispheres (halves) at a fissure (deep groove). The hemispheres communicate with each other through the corpus callosum. The two hemispheres are in continual communication with each other, acting as independent parallel processors with complementary functions. Each hemisphere of the brain is divided into four lobes: occipital, parietal, frontal and temporal. Surprisingly, each hemisphere controls muscles and glands on the opposite side of the body. The cerebrum controls language, conscious thought, hearing, somatosensory functions (sense of touch), memory, personality development, and vision (Richard and Snell; 2001)

Gray matter (unmyelinated nerve cell bodies) composes the cerebral cortex (outer portion of the cerebrum). Beneath the cortex lies the white matter (myelinated axons). During embryonic development, the cortex folds upon itself to form gyri (folds) and sulci (shallow grooves) so that more gray matter can reside within the skull cavity. The diencephalon forms the central part of the brain. It consists of three bilaterally symmetrical structures: the hypothalamus, thalamus, and epithalamus. The hypothalamus 'master switchboard' resides in the brain stem upper end. It controls many body activities that affect homeostasis (maintenance of a stable internal environment in the body). The thalamus is a relay and preprocessing station for the many nerve impulses that pass through it. Impulses carrying similar messages are grouped in the thalamus, and then relayed to the appropriate brain areas. The epithalamus is the most dorsal (posterior) portion of the diencephalon. It contains a vascular network involved in cerebrospinal fluid production. Extending from the epithalamus posteriorly is the pineal body, or pineal gland. Its function is not yet fully understood; it is thought to control body rhythms (Waxman; 2002).

At the rear of the brain is the cerebellum. The **cerebellum** is similar to the cerebrum: each has hemispheres that control the opposite side of the body and are covered by gray matter and surface folds. In the cerebellum, the folds are called folia; in the cerebrum, sulci. The vermin (central constricted area) connects the hemispheres. The cerebellum controls balance, posture, and coordination (Waxman; 2002).

The **brain stem** connects the cerebrum and cerebellum to the spinal cord. Its superior portion, the midbrain, is the center for visual and auditory reflexes. The middle section, the pons, bridges the cerebellum hemispheres and higher brain centers with the spinal cord. Below the pons lies the medulla oblongata; it contains the control centers for swallowing, breathing, digestion, and heartbeat. (Richard and Snell; 2001).

The spinal cord is a continuation of the brain stem. It is long, cylindrical, and passes through a tunnel in the vertebrae called the vertebral canal. The spinal cord has many spinal segments, which are spinal cord regions from which pairs (one per segment) of spinal nerves arise. Like the cerebrum and cerebellum, the spinal cord has gray and white matter, although here the white matter is on the outside. The spinal cord carries messages between the CNS and the rest of the body, and mediates numerous spinal reflexes such as the knee-jerk reflex (Waxman; 2002).

The peripheral nervous system (PNS) includes sensory receptors, sensory neurons, and motor neurons. Sensory receptors are activated by a stimulus (change in the internal or external environment). The PNS has two parts: the somatic nervous system and the autonomic nervous system. The somatic nervous system, or voluntary nervous system, enables humans to react consciously to environmental changes. It includes 31 pairs of spinal nerves and 12 pairs of cranial nerves. This system controls movements of skeletal (voluntary) muscles (Richard and Snell; 2001).

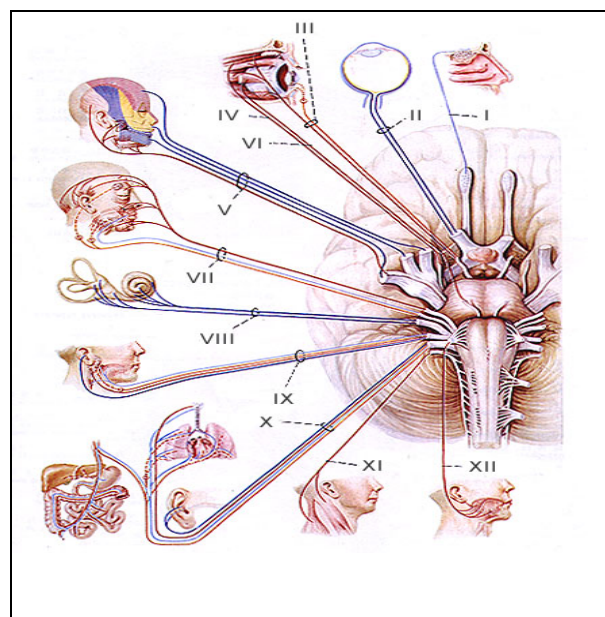


Figure 3. Cranial nerves

Thirty-one pairs of spinal nerves emerge from various segments of the spinal cord. Each spinal nerve has a dorsal root and a ventral root. The dorsal root contains afferent (sensory) fibers that transmit information to the spinal cord from the sensory receptors. The ventral root contains efferent (motor) fibers that carry messages from the spinal cord to the effectors. Twelve pairs of cranial nerves transmit from special sensory receptors information on the senses of balance, smell, sight, taste, and hearing. Cranial

nerves also carry information from general sensory receptors in the body, mostly from the head region (Rakel; 2002).

2.3 Traumatic brain injury definition:

TBI is an insult to the brain caused by external physical force. Campbell (2000: 19) differentiates **TBI** from degenerative or congenital brain lesions in that **TBI** is caused by trauma to the head including the effects upon the brain or other possible complications of injury notably such as brain hypoxemia and intracranial or cerebral haematoma. **TBI** has immediate and subsequent complications. Immediate complications involve cognitive, physical, behavioral, emotional, communication and activities of daily living deficits. Subsequent complications involve pressure sores, muscle contractures, heterotopic ossifications, epilepsy and death. These deficits may be either temporary or permanent.

2.3.1 Types of traumatic brain injury:

TBI can be classified according to severity, injury and causes (CDC; 2006, Randall and Braddom, 2000).

2.3.1.1 Severity of traumatic brain injury:

Randall and Braddom (2000) define **severe brain injury** as an injury to the brain resulting in a loss of consciousness more than six hours and a Glasgow Coma Scale (**GCS**) of three to eight (GCS measures consciousness level; minimum score = 3/15, coma; maximum or best =15/15). Comatose individual doesn't open the eyes and does not demonstrate motor nor verbal response. Sever **TBI** accounts for the large majority of individuals in acute brain injury rehabilitation units. On other hand the prognosis the large majority of sever **TBI** has permanent neurological and neuropsychological impairments that result in functional disabilities.

Moderate brain injury results in a loss of consciousness from 20 minutes to 6 hours and **GCS ranges between** 9 and 12. Individual's level of consciousness is combative or lethargic (drowsy). Moderate **TBI** accounts for a minority of individuals in acute **TBI** rehabilitation. The time needed to reach maximal neurological recovery from moderate **TBI** is shorter than that from sever **TBI**. Persons with moderate traumatic brain injury generally can make a good recovery with treatment or successfully learn to compensate for their deficits (Randall and Braddom; 2000).

Individuals who have loss of consciousness and/or confusion and disorientation shorter than 30 minutes are diagnosed as **mild** brain injury. While Magnetic Resonance Imaging (MRI) and Computed Tomography (CT) scans are often normal, the individual has cognitive problems such as headache, difficulty thinking, memory problems, attention deficits, mood swings and frustration. These injuries are commonly overlooked, however; they account as most prevalent **TBI**. The outcome of a single uncomplicated mild **TBI** to a child or young adult generally is return to pre-injury activities, without detectable cognitive impairments. The time needed for neurological recovery from mild **TBI** in such cases is at most three months and probably less than one month in most cases. Mild **TBI** also named as concussion, minor head injury, minor head trauma or minor **TBI** (Cuccurullo; 2004).

2.3.1.2 Types of traumatic brain injury according to injury:

There are two major types of **TBI**: penetrating and closed head injury. In **penetrating** injuries a foreign object, for example, a bullet enters the brain and causes damage to specific brain parts. This focal, or localized, damage occurs along the route the object has traveled in the brain. Symptoms vary depending on the part of the brain that is damaged. **Closed** head injuries result from a blow to the head as occurs, for example, in a car accident when the head strikes the windshield or dashboard (Rakel; 2002).

TBI causes primary and secondary brain damage. Primary brain damage occurs at the time of impact and may involve skull fracture (breaking of the bony skull), contusions/bruises, haematoma, lacerations and nerve damage. Contusions (bruises) often occur right under the location of impact or at points where the force of the blow has driven the brain against the bony ridges inside the skull. **Haematoma (blood clots)** occurs between the skull and the brain or inside the brain itself. **Lacerations** refer to tearing of the frontal (front) and temporal (on the side) lobes or blood vessels of the brain; the force of the blow causes the brain to rotate across the hard ridges of the skull, causing the tears. **Nerve damage (diffuse axonal injury)** arises from a cutting or shearing force from the blow that damages nerve cells in the brain's connecting nerve fibers (Barbara et al; 1996).

Secondary brain damage evolves over time after the trauma, may include: brain swelling (edema), low sodium, low or high blood pressure, increased pressure

inside of the skull (intracranial pressure), Epilepsy, Intracranial infection, Fever, Hematoma, Lung changes, Anemia, cardiac changes, too much or too little carbon dioxide, abnormal blood coagulation and nutritional changes (Stokes, 2004:104).

2.3.1.3 Causes:

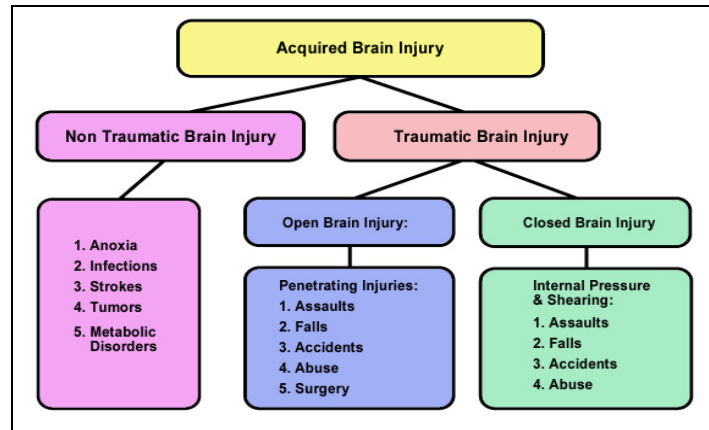


Figure 4. Causes of TBI

A traumatic brain injury (**TBI**) is caused by a blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. According to the National Centre for Injury Prevention and Control (CDC; 2006), falls (28%), motor vehicle-traffic crashes (20%), struck by/against events (19%) and assaults (11%) are the most common causes of **TBI**. Struck by or against events include colliding with a moving or stationary object and is the third leading cause of **TBI**. There are less common causes of **TBI** such as pedal cycle (3%), other transport (2%) and suicide (1%).

Falls are the leading cause of **TBI**; rates are highest for children ages 0 to 4 years and adults' ages 75 years and older. Motor vehicle-traffic causes result in the greatest number of **TBI**-related hospitalizations. The rate of motor vehicle-traffic-related **TBI** is highest among adolescents' ages 15 to 19 years (CDC; 2006).

Firearm use is the leading cause of death related to **TBI**; Nine out of 10 (90%) people with a firearm-related **TBI** die. However, nearly two thirds of firearm-related **TBIs** are classified as suicidal in intent. Blasts are a leading cause of **TBI** for active duty military personnel in war zones (CDC; 2006).

2.4 Complications:

TBI has immediate neurological symptoms such as loss of consciousness and paralysis. However, **TBI** individual may develop later symptoms or complications.

2.4.1 Immediate (early) complications:

Health complications occur in the period immediately following a **TBI**. These complications are not types of **TBI**, but are distinct medical problems that arise as a result of the injury. Immediate complications of **TBI** may include Postconcussion syndrome, seizures, enlargement of the fluid-filled chambers within the brain (hydrocephalus or post-traumatic ventricular enlargement), leaks of cerebrospinal fluid, infection, and injury to blood vessels or to the nerves supplying the head and neck, pain, bed sores, failure of multiple organ systems, and trauma to other areas of the body.

2.4.1.1 Postconcussion syndrome:

Within days to weeks of a head injury approximately 40% of **TBI** survivors develop troubling symptoms called postconcussion syndrome (PCS). A person need not have suffered a concussion or loss of consciousness to develop the syndrome and many people with mild **TBI** suffer from PCS. Symptoms include headache, dizziness, vertigo (a sensation of spinning around or of objects spinning around the person), memory problems, trouble concentrating, sleeping problems, restlessness, irritability, apathy, depression, and anxiety. These symptoms may last for a few weeks after the head injury. The syndrome is more common in individuals who had psychological symptoms such as depression or anxiety before the injury. Treatment for PCS may include medicines for pain and psychological conditions, and counseling to develop coping skills (Cuccurullo; 2004).

2.4.1.2 Seizures:

Rakel (2002) defined Seizures as a sudden change in behavior characterized by changes in sensory perception (sense of feeling) or motor activity (movement) due to an abnormal firing of nerve cells in the brain. About 25 percent of individuals with brain contusions or hematoma and about 50 percent of individuals with penetrating head injuries will develop seizures within the first 24 hours of the injury. These seizures generally stop within a week. Doctors typically only treat these seizures if they continue beyond a week. Seizures occurring more than one week after injury are referred to as

post-traumatic epilepsy and are treated with medications. The medications may need to be taken by the survivor for months or years following the injury (Rowland; 2005).

2.4.1.3 Hydrocephalus:

Our brains continually produce and drain a fluid called cerebrospinal fluid (CSF). White et al, (1998) defined Post-traumatic hydrocephalus (PTH) is a medical complication of (TBI); An excessive accumulation of cerebrospinal fluid within the cranium which may be associated with dilation of cerebral ventricles. When the brain is injured the drainage of CSF may be affected and CSF may build up. The build-up of fluid can lead to increased pressure in the brain. Hydrocephalus may begin during the early stages of TBI but not be apparent until much later. However, it usually is diagnosed within the first year after the injury. Symptoms can include a decreased level of consciousness, changes in behavior, lack of coordination or balance, and loss of the ability to hold urine. Treatment may include draining CSF through a small plastic tube called a shunt. The shunt typically runs under the skin from the head to the abdomen where the fluid drains and is reabsorbed by the body (Sleever and chinarian; 1997).

2.4.1.4 Leakage of cerebrospinal fluid:

Skull fractures can tear the membranes that cover the brain, leading to leakage of cerebrospinal fluid(CSF).While the leaking fluid may be trapped between the membranes that surround the brain, it may also leak out of the nose or ears. CSF leakage ceases after head elevation, alone, for a few days in 85% of cases. If it persists surgery may be necessary to repair the fracture and stop the leakage. This leakage of CSF may cause serious complication such as infection, meningitis and encephalitis (Rowland; 2005).

2.4.1.5 Infections:

Tears that let CSF out of the brain cavity can also allow air and bacteria into the cavity. An infection of the membrane around the brain is called meningitis and is a dangerous complication of TBI. Most infections develop within a few weeks of the initial trauma and result from skull fractures or penetrating injuries. Standard treatment includes antibiotics and sometimes surgery to remove the infected tissue (White et al; 1998).

2.4.1.6 Damaged blood vessels in the brain:

Any injury to the head or brain usually results in some damage to blood vessels in the brain. While the body usually quickly repairs damage to small blood vessels, an

injury to larger vessels can result in serious complications. Damage to a major artery supplying blood to the brain can cause a stroke in one of two ways: **1-** Bleeding from an artery (called a hemorrhagic stroke), or **2-** A blood clot that forms in an injured artery. When a clot forms in a major artery it can block blood flow, depriving the area that the artery supplies with blood of needed oxygen and nutrients (known as an ischemic stroke). Symptoms of a blood clot in the head include headache, vomiting, seizures, paralysis on one side of the body, and decreased consciousness level (Randall and Braddom; 2000).

2.4.1.7 Pressure Ulcer:

Pressure Ulcer (PU): Also called bed sore or recumbent ulcer or decubitus ulcer. PU is an area of erythema under the skin which may progress to ulceration and subcutaneous tissue necrosis a result of ischemia due to unrelieved pressure (Barns and Ward; 2004) Pressure ulcers are the primary complication for people with **TBI**. Associated with a marked increase in length of hospital stay. More likely to appear in malnourished persons who are in a negative nitrogen balance. Could be so massive that it takes months or years of treatment and costs thousands of dollars to repair while individual's mobility will be further limited. Common Locations for PU formation depends on position of individual, *Supine*: Occiput, shoulders, elbows, sacrum and heels, *Side-lying*: Ears, shoulder, trochanter, knee, area between knees, Ankles, *Sitting on wheel chair*: Scapula, sacrum, Ischium, trochanters, heels, Bottom of feet.

2.4.1.8 Pain:

Lahz and Bryant Show in study (1996) chronic pain is a significant problem in mild, moderate and severe **TBI** individuals. Pain is a common symptom of **TBI** and can be a significant complication for conscious individuals in the period immediately following a **TBI**. Posttraumatic Headache (PTHA) is the most common frequent type of pain associated with mild traumatic brain injury (Martelli et al; 1999).

2.4.1.9 Cranial Nerve Injuries:

Cranial nerves are nerves running from the brain through openings in the skull and to areas in the head such as the eyes, ears, and face. Skull fractures, especially at the base of the skull, can injure cranial nerves. The seventh cranial nerve, called the facial nerve, is the most commonly injured cranial nerve in **TBI**. An injured facial nerve can result in paralysis of facial muscles. When facial muscles are paralyzed, facial

expressions such as smiling will not be symmetrical. Nerve injuries may heal spontaneously. If they do not, surgery may, in certain circumstances, be able to restore nerve function (Rowland;2005). Schalén et al (1994) show 40-50% of these individuals showed co-ordination disturbances.

2.4.1.10 General Trauma:

When a **TBI** occurs there is usually trauma to not only the brain but other parts of the body as well. These injuries require immediate and specialized care and can complicate treatment of and recovery from the **TBI**.

2.4.2 Later complications:

In addition to the immediate post-injury complications discussed on previous paragraphs other long-term problems can develop after a **TBI**. These include Pulmonary, Thrombophlebitis, Gastrointestinal and nutritional, Incontinence, Heterotopic ossifications, Spasticity, osstumatic hyperthermia, cognitive disorders language and communication, sleep disorders, sexual and reproductive functioning and coma.

2.4.2.1 Pulmonary complications:

When a brain injury occurs, the lungs and the alveoli remain the same. However, just as the injury may affect the nerves that control the muscles of the arms and legs, it can also affect the nerves and muscles that control breathing. Individuals in coma and/or with significant paralysis are at increased risk for respiratory difficulties. Individuals who are on a ventilator (a machine supports weak breathing) or who have a tracheostomy (an open in the trachea facilitates breathing) also require close monitoring of their respiratory status. Some individuals may have trouble taking a deep breath and exhaling forcefully. They may have also lost the ability to forcefully cough or to cough with even normal force because of weakness of the intercostals and/or abdominal muscles. These breathing difficulties and the reduced ability to cough to clear the lungs can lead to lung congestion and respiratory infections (White et al; 1998).

Because of changes in respiratory function, the thick secretions of a cold or respiratory infection can accumulate causing lung **congestion**. These secretions provide

a place for the growth of bacteria. If not treated properly, pneumonia or atelectasis (collapse of the small airways of the lungs) can follow (Rakel; 2002).

Pneumonia is an infection of the lungs. The symptoms include: Pain increased secretions, Feeling of tightness in the chest, Cough weakness, fatigue, nausea and decreased appetite (Rakel; 2002).

Atelectasis is a total or partial collapse of the air sacs (alveoli) in the lung causing a lack of air to the affected area of the lung. The symptoms include shortness of breath, thick secretions with changes in color, possible pain, feeling of tightness in chest and fever (Randall and Braddom; 2000).

2.4.2.2 Gastrointestinal and nutritional complication:

Individual with **TBI** may show different gastrointestinal and nutritional problems such as increased nutritional need, Dysphagia, stress gastritis, nausea and vomiting. These complications are explained in below subchapters.

In traumatic brain injury, the metabolic response is characterized by increased metabolism and catabolism. The physiatrist and dietitian should pay attention to carbohydrate, nitrogen balance, fiber, vitamin, protein and minerals. Weekly weight as monthly measurements for many investigation are appropriate ways to monitor nutritional status during the rehabilitation phase (White et al; 1998).

Dysphagia is a Greek word that means disordered eating. According Randall and Braddom (2000) dysphagia typically refers to difficulty in eating as a result of disruption in the swallowing process. Dysphagia can be a serious threat to one's health because of the risk of aspiration pneumonia, malnutrition, dehydration, weight loss, and airway obstruction. A number of etiologies have been attributed to dysphagia in populations with neurologic and non neurologic conditions. Because of the diffuse nature of the lesion on a **TBI** injured individual, the risks of damaging structures responsible for the deglutition, e.g. cranial nerves (V, VII, IX, X, XII) and central nervous system, are greater. Disorders leading to dysphagia may affect the oral, pharyngeal, or esophageal phases of swallowing. Thorough history taking and careful physical examination are important in the diagnosis and treatment of dysphagia. The bedside physical evaluation should include examination of the neck, mouth,

oropharynx, and larynx. A neurologic examination also should be performed. Several clinical bedside swallowing assessments have been suggested, but videofluoroscopic swallowing studies are accepted as the standard for detecting and evaluating swallowing abnormalities. This method not only allows estimation of risks of aspiration and respiratory complications but also helps in determining dietary and compensatory strategies (Randall and Braddom; 2000).

Established incidence figures for Dysphagia in individuals with traumatic brain injury vary greatly depending on whether the population studied is comprised of severe **TBI** individuals, consecutive brain injury admissions, acute **TBI** individuals, or individuals in the rehabilitation phase of recovery. Morgan and colleagues (2003) found that individuals with swallowing difficulties often have concomitant cognitive impairments.

Individual with **TBI** has an increased risk of **gastrointestinal bleeding** secondary to stress ulceration during the acute care phase. Since cognitive and behavioral disturbance have been noted in individuals on H₂ antagonist, these medications should be withdrawn once the risk of gastrointestinal bleeding has passed (White et al; 1998).

Following **TBI**, **stress gastritis** can occur acutely in individuals with **TBI**. Superficial mucosal erosions can extend beyond the muscularis mucosa and develop into ulcers. The ulcers describe as Cushing ulcers (deeper and are associated with high gastrin levels and increased acid secretion). Prophylaxis with H₂ blockers and similar agents may help decrease the magnitude of this complication (Rowland; 2005).

Nausea and vomiting are the most common gastrointestinal complications. Although these appear to be relatively minor symptoms, they can increase the risk of aspiration pneumonia, interrupt therapies and cause distress to the individual and family (Randall and Braddom; 2000).

2.4.2.3 Incontinence:

Constipation or diarrhea can also be significant problems. Leary and his colleague (2006) found that incontinence was common in individuals with brain injury on a neurological rehabilitation unit. But many studies show the fecal incontinence following brain injury is fairly common, especially in individuals with significant cognitive impairments (Randall and Braddom; 2000).

2.4.2.4 Thrombophlebitis:

Incidence of deep vein thrombosis (DVT) in **TBI** is estimated to occur in up 40% to 50% of cases following major head trauma (Randall and Braddom; 2000). The venous stasis that results from muscle weakness, immobility, bone fracture, direct vascular trauma and hypercoagulability. Damage to the vessel wall can occur in **TBI** individuals as a direct result of trauma from the original injury or indirectly from external pressure on the paralyzed leg. Yablon, et al, (2004) found that deep vein thrombosis (DVT) risk is multifactorial in this heterogeneous individual population, with relative factor risk influenced by type of acquired brain injury.

2.4.2.5 Genitourinary complications:

Genitourinary complications (GU) include urinary tract infections, urethral strictures, and urinary incontinence. An appropriate workup to evaluate (GU) symptoms and rule out infection is indicated. When the causes of urinary incontinence are impaired communication and mobility, a trial of a timed voiding is indicated to manage overflow incontinence. Individuals are taken to the bathroom and given the opportunity to void without instrumentation every 2 hours during the day and every 4 hours overnight. If the individual is unable to void or unable to evacuate the urinary bladder to completion, intermittent straight catheterization may be necessary in the acute recovery period. Although not preferred, diapers and condom catheters may be needed if urinary incontinence does not improve (White et al; 1998).

2.4.2.6 Heterotopic ossifications:

Heterotopic ossifications are a complication of musculoskeletal system. Auri Bruno-Petrina (2006) explains Heterotopic ossifications (HO) as the formation of mature lamellar bone in soft tissues. The process involves true osteoblastic activity and bone formation. HO has been reported in cases of brain injury, spinal cord injury, poliomyelitis, myelodysplasia, stroke, and multiple sclerosis. This condition also has been reported after burns and total hip replacement/joint arthroplasty. Several terms have been used to describe the condition, including heterotopic ossification, ectopic ossification, and myositis ossificans. HO usually involves the large joints of the body (for example, hips, elbows, shoulders, knees). Excessive bone formation may result in significant disability by severely limiting the range of motion (ROM) of these joints. An

association has been cited between spasticity and HO. The incidence is higher in a spastic extremity; 84% of individuals with HO had spasticity. HO is seen in the elbow in 4% of individuals with (**TBI**); however, if fracture or dislocation is associated with brain injury, the incidence of HO rises to 89%. **TBI** individuals who are older than 30 years are more likely to develop HO. The incidence of HO in children (8-22.5%) appears to be lower than in adults (White et al; 1998).

2.4.2.7 Spasticity:

Spasticity is a complication caused by brain injury or spinal cord injury (upper motor neuron lesion). Spasticity (meaning to draw or tug) is involuntary, increased muscle tone resulting in resistance to movement that may occur secondary to **TBI**, velocity-dependent. Due to loss of cortical control over spinal reflex centers following an upper motor lesion, which results in increased input to or output from the spinal cord. Spasticity may be static or dynamic in nature. According Randall and Braddom (2000): although Spasticity can be beneficial, decreasing the risk of Thrombophlebitis and it can create impressive deformity, pain and other medical complications. This can cause unwanted and involuntary motor phenomena when the limbs are moved actively or passively, usually an increase in flexor tone in the upper limbs, a tendency toward extensor tone in the lower limbs, and hypertonicity in the torso, face, mouth, and pharynx. Common terms include "spastic gait", "spastic elbow flexion", "spastic hand", "spastic equinovarus", and "spastic dystonia". Risk factors for early spasticity include immobilization, motor dysfunction (hemiplegia or tetraplegia). Zafonte et al (2004) found the secondary severe sequelae of spasticity after **TBI** can result in profound functional impairment.

2.4.2.8 Post-traumatic hyperthermia:

Fever (greater than 38°C) in **TBI** is common, may be result of infection or of central fever affection of brain centers that regulates body temperature. Any elevated in temperature degree should be aggressively treated. Hyperthermia is a common occurrence during recovery from trauma (Rowland; 2005).

2.4.2.9 Cognitive disorders:

"Cognition" describes the processes of thinking, reasoning, problem solving, information processing, and memory. Most individuals with severe **TBI**, if they recover

consciousness, suffer some cognitive disability. People with moderate to severe **TBI** have more problems with cognitive deficits than survivors with mild **TBI**, but a history of several mild **TBIs** (for example, a football player) may have a cumulative effect. Recovery from cognitive deficits is greatest within the first six months after the injury and is usually more gradual after that. Most improvements can be expected within two years of the injury (Catherine; 1989).

The most common cognitive impairment among severely head-injured survivors is **memory loss**, characterized by some loss of older memories and the partial inability to retain new memories. Some of these individuals may experience post-traumatic amnesia, which can involve the complete loss of memories either before or after the injury. Many survivors with even mild to moderate head injuries who experience cognitive deficits become easily confused or distracted and have problems with **concentration** and **attention** (Turner et al; 1997).

Individuals with a mild to moderate **TBI** also have problems with higher level, so-called **executive functions**, such as planning, organizing, abstract reasoning, problem solving, and making judgments. This disability may make it difficult to return to the same job or school setting the individual was in before the injury (Turner et al; 1997).

2.4.2.10 Language and communication:

Language and communication are frequent problems for **TBI** survivors. Some individuals have trouble recalling words and speaking or writing in complete sentences (called non-fluent aphasia). They may speak in broken phrases and pause frequently. They are usually aware of what is happening and may become extremely frustrated (Turner et al; 1997).

Schalén et al., (1994) found in their study there are more than 20% had speech disorders and cranial nerve deficits. Other survivors may speak in complete sentences and use correct grammar but for the listener the speech is pure gibberish, full of invented or meaningless words (called fluent aphasia). **TBI** survivors with this problem are often unaware that they make little sense and become angry with others for not understanding them (Jonathan et al; 2005)

Other survivors can think of the appropriate language but cannot easily speak the words because they are unable to use the muscles needed to form the words and produce the sounds (called dysarthria). Speech is slow, slurred, and garbled (Turner et al; 1997)

2.4.2.11 Emotional and Behavioral Problems:

Hurley and Taber (2002) found that most **TBI** survivors have some emotional or behavioral problems. Family members often find that personality changes and behavioral problems are the most difficult disabilities to deal with. Emotional problems can include depression, apathy, anxiety, irritability, anger, paranoia, confusion, frustration, agitation, difficulty sleeping, and mood swings. Problem behaviors may include aggression and violence, impulsiveness, loss of inhibitions, acting out, being uncooperative, emotional outbursts, childish behavior, impaired self-control, impaired self awareness, inability to take responsibility or accept criticism, being concerned only with oneself, inappropriate sexual activity, and alcohol or drug abuse. Sometimes **TBI** survivors stop maturing emotionally, socially, or psychologically after the trauma which is a particularly serious problem for children and young adults. Many **TBI** survivors who show psychiatric or behavioral problems can be helped with medication and psychotherapy (Jonathan et al; 2005).

2.4.2.12 Sleep Disorders:

Nearly all of head-injured individuals have some form of sleep disorder. Parcell (2006) found that individuals with **TBI** have higher rates of sleep changes than do sex-matched control subjects (80% for **TBI** vs. 23% for non-**TBI**) The **TBI** group reported more nighttime awakenings and longer sleep-onset latency than the other group. Increased levels of anxiety and depression were risk factors that may partly account for increased complaints of excessive daytime sleepiness.

2.4.2.13 Impairment of the Senses:

Many **TBI** survivors have problems with one of the five senses, especially vision. They may not register what they are seeing or may be slow to recognize objects. Some individuals develop tinnitus, a ringing or roaring in the ears. Others may develop a persistent bitter taste in the mouth or complain of a constant foul smell. Some **TBI** survivors feel persistent skin tingling, itching, or pain. Although rare, these conditions are hard to treat (Rowland; 2005).

TBI survivors often have difficulty with hand-eye coordination. Because of this, they may be prone to bumping into or dropping objects or may seem generally unsteady. They may have difficulty driving a car, working complex machinery and playing sports (Jonathan et al; 2005).

2.4.2.14 Sexual and reproductive functioning:

In people with brain injury, sexual dysfunction depends on the severity of the neurologic impairment and the site of the damage to brain structures. A high degree of physical independence and maintained sexual ability are among the most important predictors for sexual adjustment. The impact of **TBI** on sexual function is often neglected in the course of recovery. Frontal lobe lesions and right hemisphere injuries are predictive of higher sexual satisfaction and functioning than other lesions, and individuals with more recent injuries have reported greater levels of arousal than those less recently injured (Sandel, et al; 1996). The main sexual problems are; Amenorrhea and menstrual irregularities are common, although the cycle usually returns within the first several months, Decreased libido, decreased sexual performance, impotence, and decreased sexual drive and satisfaction/orgasm are the most common changes following **TBI**. Anterior pituitary dysfunction following **TBI** is common, but hypopituitarism is treatable. Women with **TBI** in one study had more positive feelings about their sexuality than did men with **TBI** (Agha et al; 2004).

2.4.3 Complications for Unconscious Individuals:

Individuals may have serious complications if still are unconscious, in a coma, or in a vegetative state includes bed or pressure sores of the skin, repeated bladder infections, pneumonia or other life-threatening infections, and the failure of multiple organs, such as the kidneys, lungs, and heart.

2.4.3.1 Coma:

Coma, from the Greek word "koma," Stokes (2004) defined coma as not obeying commands, not uttering words and not opening eyes. Coma is a prolonged period of unconsciousness. Coma differs from sleep in that one cannot be aroused from a coma.

In order to understand the loss of function suffered by a comatose individual, it is necessary to first understand the important characteristics of the conscious state. Consciousness is defined by two fundamental elements: awareness and arousal.

Awareness allows one to receive and process all the information communicated by the five senses, and thus relate to oneself and to the outside world. Awareness has both psychological and physiological components. The psychological component is governed by an individual's mind and mental processes. The physiological component refers to the functioning of an individual's brain, and therefore that brain's physical and chemical condition. Awareness is regulated by cortical areas within the cerebral hemispheres, the outermost layer of the brain that separates humans from other animals by allowing for greater intellectual functioning (Cuccurullo; 2004).

Arousal is regulated solely by physiological functioning and consists of more primitive responsiveness to the world, as demonstrated by predictable reflex (involuntary) responses to stimuli. Arousal is maintained by the reticular activating system (RAS). This is not an anatomical area of the brain, but rather a network of structures (including the brainstem, the medulla, and the thalamus) and nerve pathways, which function together to produce and maintain arousal (Rowland; 2005).

Two scales of measurement often used in **TBI** diagnosis to determine the levels of coma are the Glasgow Coma Scale (GCS) and the Ranchos Los Amigos scale (RLAS). The GCS is a simple 15-point scale used by medical professionals to assess severity of neurological trauma, and establish a prognosis. Glasgow Coma Scale is the standard measurement of coma in the acute phase. This scale measures the depth of coma, based on motor response, eye opening, and vocal response. Ratings range from 3 -15. Total rating of 3 -5 indicates very severe brain injury and Total rating of 6 - 8 indicates severe brain injury (still in coma). Total rating of 9 - 15 indicates brain injury out of coma which includes: Total rating of 9 - 12 indicates moderate **TBI** and Total rating of 13 - 15 indicates mild **TBI** (Cuccurullo; 2004).

The RLAS is a more complex scale that has eight separate levels, and is often used in the first few weeks or months of coma while the individual is under closer observation, and when shifts between levels are more frequent.

Coma is a medical emergency, and attention must first be directed to maintaining the individual's respiration and circulation, using intubations and ventilation, administration of intravenous fluids or blood as needed, and other supportive care. If head trauma has not been excluded, the neck should be stabilized in the event of fracture. It is obviously extremely important for a physician to determine

quickly the cause of a coma, so that potentially reversible conditions are treated immediately. For example, an infection may be treated with antibiotics; a brain tumor may be removed; and brain swelling from an injury can be reduced with certain medications. Various metabolic disorders can be addressed by supplying the individual with the correct amount of oxygen, glucose, or sodium; by treating the underlying disease in liver, asthma, or diabetes; and by halting seizures with medication. Because of their low incidence of side effects and potential for prompt reversal of coma in certain conditions, glucose, the B-vitamin thiamine, and Narcan (to counteract any narcotic-type drugs) are routinely given (Stokes; 2004).

Some conditions that cause coma can be completely reversed, restoring the individual to his or her original level of functioning. However, if areas of the brain have been sufficiently damaged due to the severity or duration of the condition which led to the coma, the individual may recover from the coma with permanent disabilities, or may even never regain consciousness. In the event of a less severe brain injury, with minimal swelling, an individual may indeed recover consciousness and regain all of his or her original abilities. In the event of a more severe brain injury, with swelling that resulted in further pressure on areas of the brain, an individual may regain consciousness, but may have some degree of impairment. The impairment may be physical (such as paralysis of a leg) or may even result in a change in the individual's intellectual functioning and/or personality. The most severe types of brain injury, short of death, result in states in which the individual loses all ability to function and remains deeply unresponsive. An individual who has suffered such a severe brain injury may remain in a coma indefinitely. This condition is termed persistent vegetative state (Catherine; 1989).

Outcomes range from recovery to death. Comas generally last a few days to a few weeks, rarely more than 2 to 5 weeks. After this time, some individuals gradually come out of the coma, some progress to a vegetative stage, and others die. Many individuals who have entered a vegetative state go on to regain a degree of awareness. Others remain in a vegetative state for years or even decades. The outcome for coma and vegetative state depends on the cause, location, severity and extent of neurological damage. A deeper coma alone does not necessarily mean a slimmer chance of recovery, because some people in deep coma recover well while others in a so-called milder coma sometimes fail to improve (Rowland; 2005).

People may emerge from a coma with a combination of physical, intellectual and psychological difficulties that need special attention. Recovery usually occurs gradually -- individuals acquire more and more ability to respond. Some individuals never progress beyond very basic responses, but many recover full awareness. Regaining consciousness is not instant: in the first days, individuals are only awake for a few minutes, and duration of time awake gradually increases (Catherine; 1989).

The most common cause of death for a person in a vegetative state is secondary infection such as pneumonia which can occur in individuals who lie still for extended periods (Rowland; 2005).

The severity of coma impairment is categorized into several **levels**. Individuals may or may not progress through these levels. In the first level, the brain responsiveness lessens, normal reflexes are lost, and the individual no longer responds to pain and cannot hear (Randall and Braddom; 2000).

Contrary to popular belief, an individual in a coma does not always lay still and quiet. They may talk, walk, and perform other functions that may sometimes appear to be conscious acts but are not.

The term **coma** is used to describe to a state of sustained unresponsiveness to external stimuli. Other states of impaired arousal or awareness can also be described. **Stupor** described as individual who is arousable with vigorous and repeated stimuli but whose response is slow or inadequate. **Obtundation** describes a lesser state of decreased arousal, with some responsiveness to voice or touch. **Lethargy** (somnia) is a state of diminished arousal that can be maintained spontaneously or by light repeated stimulation. **Confusion** and **delirium** refer to states of alertness with impaired cognition (Rakel; 2002).

2.5 Epidemiology of TBI:

Traumatic Brain Injury is a modern scourge of industrialized society. It's the major cause of death and disability. According to Smith (2005), **TBI** during childhood constitute a major medical and public health problem. Approximately 4.000 children die each year of head injuries in the United States (CDC; 2006). The epidemiology of **TBI**, including incidence, prevalence, etiology, and natural history, can guide to estimates of the demand for and range of required **TBI** rehabilitation services. Recent review summarizing major epidemiological studies in the USA estimate that the annual

incidence of hospitalized **TBI** is a proximally 40% of all deaths from acute injuries in the United States. Annually, 200,000 victims of **TBI** need hospitalization, and 1.74 million persons sustain mild **TBI** requiring a physician visit or temporary disability of at least 1 day (CDC; 2006). The incidence of **mild TBI** is about 131 cases per 100,000 people, but it could be double. The estimate based on hospital admissions because many mild **TBI individual** fail to seek medical attention or are discharged home from the emergency department. So the newer methodologies to assess the epidemiology of mild **TBI** that does not result in hospitalization should be developed and its incidence and prevalence rigorously studied.

The incidence of **moderate TBI** is about 15 cases per 100,000 people. The incidence of **severe TBI** is about 14 cases per 100,000 people. Prevalence estimates range from 2.5 million to 6.5 million individuals living with the consequences of **TBI** in the USA. These estimates, however, suffer from ascertainment bias since they are based exclusively on information about hospitalized patients and those who die before hospitalization. These epidemiologic profiles indicate that **TBI** is extremely heterogeneous. This is apparent in the distribution of **TBI** by age, gender, ethnicity, severity, and cause (CDC; 2006).

Estimates by the National Institute of Health; (2004) Consensus Development Panel on Rehabilitation of Persons with **TBI** showed that 2.5-6.5 million Americans live with **TBI**-related disabilities. The risk of **TBI** is highly predictable from demographic factors. Males are more than twice as likely as females to experience **TBI**. The two age groups at highest risk for **TBI** are 0 to 4 year olds and 15 to 19 year olds. Adults age 75 years or older have the highest rates of **TBI**-related hospitalization and death. There are no reliable global statistics for **TBI** (CDC; 2006).

The researcher reviewed the annual reports issued by the Palestinian Ministry of Health for the years 2004 and 2005 and she didn't find relevant significant data to be reported in this study. The Palestinian bureau centre for statistics reported that there is no available data relevant to **TBI**. They added that a report will be issued in the next year (A visit to the Palestinian bureau centre for statistics on Saturday, Feb 05, 2008 – Reported by: Mohamed Quhman).

2.6 Traumatic brain injury evaluation:

On admission to emergency room, resuscitation measures, history taking and examination should begin simultaneously, and evaluation begins. Computed Tomography (**CT**) is the emergency imaging method of choice for head injury. **CT**

images should be assessed for the presence of epidural or subdural hematomas, subarachnoid or interventricular blood, parenchymal contusions, hemorrhages, cerebral edema and gliding contusions. Magnetic Resonance Imaging (**MRI**) is better for detecting subtle injury to the brain. Generally not used for emergency evaluations unless it is rapidly and readily available. After the initial neurologic assessment, a more detailed physical and neurologic examination should be performed. The skull should be palpated for fractures, hematomas and lacerations. The **TBI** individual should be thoroughly examined for external signs of trauma to the neck, chest, back, abdomen and limbs. Bloody discharge from the nose or ear may indicate leakage of CSF. After determining the **TBI** individual's level of consciousness (alert, lethargic, somnolent, or comatose), a focused mental – status examination should be performed if the -patient- is conversant. Particular attention should be paid to attention capabilities, concentration, orientation and memory, included assessment for retrograde and anterograde amnesia. Eye movements, papillary size and shape, and reactivity to light should be noted. Motor examination should focus on identifying asymmetric weakness or posturing. Gait, balance and equilibrium tested by tandem heel – toe walking (Rowland; 2005).

The evaluation of **TBI** individual may need to be done in several brief sessions because of the **TBI** individual's reduced endurance. He may be at higher level in the morning and regress with fatigue or he may demonstrate dominantly lower level neurological responses. The health team members evaluated the **TBI** individual as each discipline is assessing different aspects of the individual's responsiveness and function. In recovery stage, not all **TBI** individuals will experience all the stages of recovery. In some way show initial responses of a higher neurological level. Still other **TBI** individual may stop at one level and plateau there indefinitely. The **TBI** individual should be examined repeatedly to evaluate level of consciousness and the presence or absence of signs of injury to the brain or cranial nerves.

2.6.1 Hospital phase:

Hospital phase is required for those with more severe and acute physical, cognitive and behavioral deficits. Hospital or subacute unit (in-patient) of the medical center, it is organized within skilled nursing facilities or other long-term care settings. These programs are designed for patients that are too medically fragile or dependant to be cared for at home but who are not yet able to tolerate or benefit from the intensive

efforts of acute rehabilitation. After initial hospitalization, moderately and severely **TBI** individuals, multitrauma or the systemic illness may still in subacute unit. And may receive daily therapy to prevent secondary complications and work toward goals of greater independent functions. The interdisciplinary team may culminate in admission to and acute rehabilitation program or a planned discharge to an organized home – and based service system of care (Smith; 2005).

Medications used with the **TBI** individual must be carefully selected and closely monitored because of their potentially deleterious side effects such as Tegretol and Phenobarbital which are common used to prevent or reduce seizure activity. Other medications can be given such as Dizepam, phenytoin and baclofen (Ruth and Ben; 2000).

2.6.2 Rehabilitation phase:

As with all rehabilitation, the goal is to help the person achieve the maximum degree of independence in order to return to their previous level of functioning and improve the **TBI** individual's ability to function at home and in community regardless of the residual effects of the injury, which may be complex and multifaceted. **TBI** rehabilitation is best managed by a specialized interdisciplinary team of health professionals. **TBI** rehabilitation often consists of two phases - inpatient and community management. Rehabilitation is an important and critical part of the recovery process for a **TBI**. Moderately and severely injured **TBI** individuals need to receive specialized rehabilitation treatment that draws on the skills and knowledge of many specialists, involving treatment programs in the areas of physician, nurse, physical therapy, occupational therapy, speech/language therapy, psychology, psychiatry and social work. Once medically stable, the individual may be transferred to a long-term acute care facility, to a rehabilitation inpatient treatment unit. This treatment program is generally provided through a coordinated and self-organized process in the context of a team healthcare delivery. **TBI** individual has been discharged from the inpatient rehabilitation treatment unit. The outpatient phase of care begins and goals often will shift from assisting the person to achieve independence in basic of activities daily living (ADL) to community inclusion. Community rehabilitation follows discharge from an inpatient rehabilitation service. Helping a person with **TBI** return to maximum level of independence and participation in the community is an extremely difficult task. Family

support, education and counseling are vital and likely to be needed for a prolonged period.

The focus is on issues such as Post-traumatic amnesia (PTA) monitoring, retraining in activities of daily living, pain management, cognitive and behavioral therapies, pharmacological management, assistive technology (for example, prescription wheelchairs and gait aids), environmental manipulation (for example, installation of lifts, ramps and rails, and bathroom alterations), as well as family education and counseling. Most **TBI** individuals also require rehabilitation for associated trauma (such as fractures). **TBI** individuals may also require retraining in daily living activities for home and community living. This can be done through outpatient programs or through a transitional living unit, where **TBI** individuals are largely self-managing under health professional supervision.

2.7 Traumatic brain injury management:

The immediate goal of **TBI** individuals' management is to assess and stabilize the airway, respiration and circulation. The management of **TBI** individual can be classified according Rowland (2005) into three groups based on risk: low, moderate and high. *Low risk* group includes criteria such as normal neurologic examination, no concussion, may complain of headache and dizziness and may have scalp abrasion or laceration or hematomas, and absence of moderate or severe injury criteria. *Moderate risk* group includes criteria such as GCS score 9- 14 ,concussion, post traumatic amnesia, vomiting, seizure, signs of possible depressed skull fracture of serous facial injury. *High risk* group which includes criteria such as GCS of 3-8 (comatose), progressive decline in level of consciousness, focal neuralgic sings, penetrating skull injury or palpable depressed skull fracture.

TBI individuals with *low risk* criteria may be discharged from the emergency room without CT, so should be observe for the next 24 hours for any symptom of **TBI** such as vomiting or deterioration of consciousness level. This type of **TBI** management is known as conservative treatment as there is no surgical intervention. Among patents that have experienced *a moderate – risk* group should be admitted to an intermediate or intensive care unit (ICU) for observation. A follow-up CT at 24 hours is often helpful to check for progression of bleeding. All individuals with a severe **TBI** are admitted to the hospital. Medical management of severe **TBI** should take place in an ICU.

Neurosurgical consultation is crucial, emergency surgery is an indication in this stage. ICU care may play a major role in reducing secondary brain injury that develops over hours or days (Rowland; 2005).

Medical stability, cognitive level and the ability to benefit from intensive rehabilitation are used to identify the appropriate time for transfer rehabilitation phase (Cuccurullo; 2004).

2.7.1 Acute and subacute management:

Initial acute treatment focuses on saving the victim's life. Rescue or emergency personnel unblock airways, assist breathing, and keep blood circulating. The acute rehabilitation is characterized by inpatient hospital units and services. This program provides a full spectrum of services to help the **TBI** individual resume full living, including: physical therapy, occupational therapy, speech language therapy, cognitive therapy, respiratory therapy, tracheotomy care, rehabilitation nursing, psychiatry and psychology services, medication evaluation and optimization, nutrition education individual and family and recreational therapy services. Vocational rehabilitation services and case management and discharge Planning.

The main goals of subacute treatment are: early detection of complications, facilitation of neurological and functional recovery, and prevention of additional injury.

In subacute treatment, facility staff watches for and treat bedsores, muscle contractions, infections, and other complications, such as fluid accumulation in the brain (for example, hydrocephalus, subdural hygromas), that may require surgical treatment. A neurologist investigates for complications if the **TBI** individual fails to progress as expected. Neurological function often improves incompletely, so rehabilitation professionals – physical, occupational and speech therapists, nurses, neuropsychologists, neurologists, and others specializing in traumatic brain injury – help **TBI** individuals and their families understand neurological impairments. They encourage **TBI** individuals and their families to take advantage of improvements as they occur. Sometimes a **TBI** individual must learn new ways to do simple routine tasks – such as how to button a shirt or tie a shoe with one hand, or how to compensate for memory loss by using a logbook or calendar. During post traumatic amnesia (PTA), many **TBI** individuals experience poor balance, incoordination, weakness, or cognitive impairments that place them at risk for injury. They may be impulsive and unaware of their physical limitations and may try to climb out of bed or walk by themselves when it

is unsafe to do so. Agitation and restlessness may also lead to injury. A well-designed rehabilitation unit and well-trained staff can keep them safe, using little or no medication. In most cases, **TBI** individuals are discharged from the hospital once they emerge from PTA and can demonstrate, along with family and caregivers, that they will be safe in the home (Turner et al; 1997).

Medical management in the acute phase aims preservation of life and the prevention of secondary damage. The **TBI** individual typically receives computerized axial tomography scan (CT). If the CT reveals intracranial hematomas, signs of excessive bleeding or shifting of the brain immediate surgical decompression is needed. Physician from neurology, neurosurgery, internal medicine or orthopedics may direct overall medical management in the acute phase. Most of **TBI** individuals have a simple wounds of the scalp should be thoroughly cleaned and sutured. Compound fractures of the skull should be completely derided. The treatment should be performed as soon as possible but may delay until **TBI** individual is transported to a hospital. The treatment of acute subdural, epidural or parenchymal hematomas with mass effect is craniotomy and surgical removal of the clot. The bleeding should be identified and either lighted or clipped. To drain the fluid a plastic catheter is usually placed in the subdural space for several days. Rehabilitation in intensive care unit may begin as soon as neurologic stability is achieved (Rowland; 2005).

2.7.2 Team approaches:

The rehabilitation of **TBI** individuals begins during the acute stage of treatment when the issues of secondary brain injury are the greatest. After the acute phase, it is important that the clinician review the potential pharmacologic management and combine this with an interdisciplinary group of therapies, depending on what specific deficits the **TBI** individual has. The interdisciplinary team is professionals from different therapeutic disciplines. This team participates in establishing treatment priorities, goals, planning, and providing treatment. Team members contribute their respective skills, competencies, insights, and perspectives in the rehabilitation process. This also includes mutual education, communication, and alignment of expectations for the benefit of maximizing **TBI** individual outcomes. **TBI** individual, family, and case management involvement with the interdisciplinary treatment team is highly recommended. The team include; Medical, nurse Rehabilitation nurse, Physiotherapy, Occupational therapy, Psychologist, Social worker, Other medical specialties,

speech/language therapy, rehabilitation counselor and vocational rehabilitation (Smith, 2005).

Physician:

The Psychiatrist is a physician who is a specialist in physical medicine and rehabilitation. The psychiatrist is the team leader who directs the care.

Rehabilitation nurse:

Clearly plays an important role in all **TBI** individual care. Specifically with rehabilitation. This specialty includes goal setting, in-depth knowledge of wound care and skin management, adjustment to disability, bowel and bladder issues, psychological support and medication management. Most importantly, nurses encourage **TBI** individuals to be maximally independent with their care, to be involved with the goal setting process and ultimately to self direct their care.

Neurologist:

physician with special training and credentials in the area of the nervous system, who has successfully completed an approved residency in neurology.

Other medical specialties:

Neurosurgery, orthopedic surgery.

Physiotherapy:

A physical therapist will perform a thorough evaluation to assess physical impairments and functional limitations due to strength, mobility and balance deficits, as well as pain. Treatment goals will be established to restoration of range of motion to restore function. These may include: individualized exercises for strength, flexibility and balance, manual therapy, ultrasound, hydrotherapy, electrical stimulation, pain reduction methods. Later, issues of wheelchair preparation and propulsion may be important for those with sufficient impairment of mobility. Ambulation training with the appropriate assistive device should be frequently reviewed as the **TBI** individual progresses with ambulation. Safety must always be considered because the **TBI** individual with brain injury may be endangered by impulsivity or poor planning and judgment.

Occupational therapy(PT):

Occupational Therapy should address the goal as enable an individual to carry out their activities of daily living, which include those performed at work, home, school and the community, as independently as possible. Following a thorough evaluation, which includes an assessment of physical function, as well as cognitive and daily living skills. The issues of self-care, including daily activities such as dressing, bathing, and

grooming, must be addressed and emphasize the need for a planning strategy for the **TBI** individual. Cooking and driving evaluations may be needed to advise the **TBI** individual prior to his or her return to the home. Occupational Therapy provides a broad scope of therapeutic services, including: hand therapy, cognitive rehabilitation, and upper extremity splinting and adaptive equipment.

Psychologists (OT):

Are well trained in addressing psychological issues related to a brain injury. Their mandate includes not only the **TBI** individual's needs but the family's needs as well. They address issues related to adjustment to disability for the **TBI** individual and their family, depression, and sexuality issues. They also provide a variety of testing to evaluate personality issues and cognitive functioning.

Speech /language therapy(ST):

The Speech and Hearing service provides a full range of auditory and speech language pathology services, that's to improving **TBI** individual's communication, cognitive and linguistic skills, hearing and swallowing abilities. Incorporating **TBI** individual /family education components and necessary follow-up services. The ability in **TBI** individuals to swallow safely may need to be addressed. Additionally, the speech pathologist should ideally work with the neurophysiologist to identify focal cognitive needs of the **TBI** individual and to address these over a length of time. The program can help individuals who are tracheotomy or ventilator dependent or who have language delays or disorders.

Social worker:

Social worker is indispensable members of the rehabilitation team. They provide emotional support for families, evaluate living situations and coordinate disposition. In addition, they identify community services available for **TBI** individuals.

Vocational Rehabilitation:

Many **TBI** individuals will have difficulty returning to their previous level of employment. Vocational rehabilitation counselors can evaluate the **TBI** individual to determine **TBI** individual's skills and the need for training.

Therapeutic Recreation:

prepared therapist who specializes in the assessment and treatment of **TBI** in the areas of planning and management of leisure activities, time management, mental health through recreation, and community access.

Rehabilitation Counselor:

Assisting **TBI** individuals in the process of independent living, productive activity and employment. This includes assistance with financial resources, housing, community resources, social skills, vocational evaluation and treatment, **TBI** and family counseling.

Home and Community-Based Rehabilitation are rehabilitation services provided to individuals with disability or health problems at home and community settings, as opposed to a treatment facility (Smith, 2005). These services are generally accepted and widely used for individuals with **TBI** who have completed inpatient or post-acute rehabilitation. Home and community-based services may be delivered alone, or in conjunction with outpatient treatment. It is designed to maximize the transition and generalization of skills in **TBI** individuals with moderate-severe injuries from institutional settings to application in the community. In mild **TBI**, community-based services may be the primary type of appropriate intervention. One or more therapeutic disciplines are appropriate to deliver home and community based services including certified clinicians from physical therapy, occupational therapy, speech therapy, medicine, mental health, therapeutic recreation, family counseling, nursing services, and vocational rehabilitation.

2.7.4 Therapeutic approaches:

Rehabilitation team has different approaches in terms of the way the team members work, communicate, establishing treatment priorities, and decide for the therapy goals or objectives. The most common approaches are multidisciplinary and interdisciplinary. Team members contribute their respective skills, competencies, insights, and perspectives in the rehabilitation process. This also includes mutual education, communication, and alignment of expectations for the benefit of maximizing patient outcomes. Client, family and case manager also are involved in interdisciplinary rehabilitation team in addition to doctors, PT, OT, ST, psychologist and social worker.

2.8 TBI influence on life context:

Caregivers after them caring the **TBI** individuals they have changes and some modifications in their life. That's start from to preparing the **TBI** individuals for hospital discharge, early period at home, unhealthy function, adjusting new situations, coping strategies and the role changes. Rivera et al; (2007) found that caregivers of persons

with **TBI** who report physical health problems and who exhibit ineffective problem solving area are at greater risk for depression, regardless of the time they have spent in their role as a caregiver.

2.8.1 Preparing for hospital discharge (general, rehabilitation):

Preparing for discharge is highly important for clients with Traumatic Brain Injury. Those procedures include compensating for deficits that couldn't be recovered and put and client on the way to be integrated in his/her usual life. This stage begins after few progresses and slow recovery have achieved. Client-centered approach is valuable because of uniqueness of disability and life style. Procedures of this stage can be determined by priorities of client. Those priorities determine the environmental adaptations need to be done before discharge. It also important for prescription of adaptive equipment for client's daily use. Active training of using outdoor facilities and home utilities are also encouraged in this stage.

2.8.2 The early period at home:

Transition into the home can be unsettling. At home the primary responsibility for care is transferred from hospital medical staff to a family member or other caregiver. Often a family member must take on a new care-giving role that they have not experienced before. As caregiver, they may take on the added responsibilities of coordinating therapy, medical appointments, filling prescriptions, while resuming the responsibilities in their own lives. Caregivers can however, develop an orderly routine by keeping a planning calendar as they go about doing whatever it takes to establish stability during this transition time. After the chaotic disorder that everyone experienced in the days or months right after the injury, order can be very calming.

2.8.3 Unhealthy functions:

TBI caregivers have unhealthy functioning and psychological distress (Ergh et al; 2002) that's mean the assumption of a caregiving role presents challenges to the existing family system, influenced by such factors as types of support provided, role changes, and relationship patterns. To gain a beginning understanding of how families perform, and are affected by their caregiver functions, it is necessary to review potential cognitive, physical, and psychosocial effects of this type of disability with **TBI**. Sander et al, (2002) investigated the relationship between family functioning to **TBI** individuals' progress in a post-acute **TBI** rehabilitation program and they conclude the

emphasize that family functioning is an important variable to include in future models predicting rehabilitation outcome, and the importance of family intervention as part of the rehabilitation process.

2.8.4 Adjusting to new situation:

Brain injury is one of the most difficult situations to which a family must adjust (Stebbins; 1997). After injury, survivors and their families often spend time thinking about their lives and choices they have made. People think about how the injury occurred and what they can do to bring things back to where they were. Many people ask themselves difficult questions like: How have things turned out? What should I have done differently? How did things get so bad? and What should I be doing now to make things better? The family as well as the head-injured person is traumatized when a severe head injury occurs. The family is placed under extreme stress to assume unaccustomed roles, which may include caregiving, becoming breadwinners, and advocating on behalf of the injured person. This, along with the possible changes in physical functioning and personality suffered by the person with a head injury, may place an unusual burden of stress on members of the family. It is not uncommon for family members to occasionally react in ways that others do not understand. Some family members may choose to immerse themselves in efforts to help the injured family member while other family members may be emotionally unable to cope with the situation and need to distance themselves from trauma. Social adjustment after head injury is the main aspect in the adjustment after **TBI** (Oddy et al; 1985).

2.8.5 Needs for care or caregiver:

Survivors and family members often face long-term difficulties after traumatic brain injury. Many people are disappointed with the pace of recovery. Some are disappointed by the lack of resources in their home communities. Many survivors and family members have questions about getting better and the types of help that can best meet their needs. Kolakowsky-Hayner et al; (2001) assessed the life quality and long-term family needs of caregivers of persons with brain injury and they conclude: The importance of appreciating long-term family needs and other life quality issues should not be underestimated.

Caregivers of **TBI** individuals have many needs to complete the road. A recent study (Rotondi et al; 2007) investigated the expressed needs of persons with **TBI** and

their primary family caregivers. And they summarized the needs of **TBI** individuals and their caregivers as the follow: physical, social, emotional, psychological, understanding the injuries, life planning and financial needs. Kolakowsky-Hayner, et al, (2001) also reported family needs change over time, while unmet needs extend well beyond the acute setting.

2.8.5.1 Caregivers:

Caregivers assist other people who because of physical disability, chronic illness or cognitive impairment are unable to perform certain activities on their own. Caregivers may be informal or formal; *Informal care* can be offered by family members (parents, sisters, brothers, wives, husbands, and relatives) or friends, often in a home setting or paid or volunteer professional care. *Formal care* can be obtained at home, in the community or from institutions such as nursing facilities or government institutions (Seaback, 2001).

Caregivers play an important role in the recovery and reintegration processes of individuals with **TBI**. Although it is well known that changes in the **TBI** individual can result in family system disruption after **TBI**, the reverse is also true, as life changes among caregivers and family members of persons with **TBI** may stress the entire family system, including the person with injury (Campbell; 2000).

As a result of advances in medical care, more people are living longer with **TBI** individuals. The responsibility of helping those persons living with a chronic health problem often falls to family members. The role of the caregiver is not typically limited to caring for sick or disabled family members; caregivers often have multiple life responsibilities that include other family members and work obligations (Lisa; 2007).

Rivera et al, (2007) pointed out that caregivers of **TBI** individuals have physical health problems such as low back pain. Caregivers and family members play an important role in the rehabilitation process of individuals with traumatic brain injury. It is common for caregivers and family members to report feeling overwhelmed and stressed taking care of a family member with a traumatic brain injury in their home. Significant levels of distress, including anxiety, depression, and poor social adjustment. Caregivers without adequate social support were increasingly distressed as time went on, whereas caregivers with adequate social support were not. The amount of family dysfunction was associated with the amount of perceived social support. Caregivers perceiving the lowest social support reported the highest levels of distress and family

dysfunction (Ergh et al; 2002). The same author's and colleagues in (2003) found that Social support emerged as an important moderator of life satisfaction in **TBI** caregivers.

Serio, et al; (1997) suggest that information, emotional support, and practical advice are highly valued by family members within the first few years following the injury date. Brener et al; (2004) estimate healthcare expenditures of children with mild to moderate traumatic brain injury (**TBI**) outside of acute care settings. And they found the total of costs of **TBI** in children are high; so that's give over load in their caregivers (families). Finical support very importance for the **TBI** career.

2.8.6 The influence of ongoing TBI individuals' care on caregivers' life:

Each person in a family has specific roles they fulfill. Traditionally the mother may be the "emotional caretaker" of the family (Parcell; 2006). When personal crisis occur to a family member, the mother will provide emotional nurturance and support to that member. The father may have the "breadwinner" role, either primarily or singly for the family. A son or daughter may take on specific roles as well. For example, the oldest son may feel a responsibility to watch over the safety of the family in the father's absence. A daughter may provide motherly care for a younger sibling if the mother is not at home. When a person sustains a brain injury, that person may not be able to fulfill his or her previous role in the family. If for example, the husband was injured, the main source of financial income to the family, the whole family may suffer the financial loss. The family may then reorganize such that the wife will work and bring in an income, thus taking over the role of "family breadwinner". In the same family, the wife customarily provided emotional support to other family members but after her husband's injury, no longer has the time to provide the same amount of emotional nurturance. Other family members may suffer the loss of not having their usual emotional support available in times of need. This can change the family system. However, if another member provides sufficient emotional care, thus fulfilling the "emotional supporter" role, the family successfully reorganizes and has its needs met. Thus families can make functional/healthy responses to change within the family system by reassigning new roles to appropriate members while allowing individual members to meet their own personal needs and pursue their own goals. Unhealthy or dysfunctional responses are evident when family members remain rigid in their customary roles, unable or unwilling to compensate for the decreased functioning of the injured member. Therefore important duties and responsibilities are left unfulfilled often

to the detriment of the family. Decline in initial denial and better recognition by the family of chronic deficits and their impact on family members often were cited as causes of increased distress in families over time (Lezak, 1988). If one of the parents becomes brain injured, an older son or daughter may take over some of the parenting roles for any younger siblings. This child "grows up quickly" in an effort to manage those responsibilities that were once filled by the injured parent.

When the brain damaged child is in the home, the caretaker "usually the mother" is likely to become the focus of competition between the injured child on the one hand and the other parent and other children for her attention. Frequently marital conflict results as parents disagree over who is to care for the child and how, and the father feels neglected by the exhausted mother who copes with the child all day. Resnick, (1993) found that there is a break down in marital relationships in family with **TBI** individual. The siblings of the head injured child may come to resent their brother/ sister because of possible increased attention given to the survivor, or the sibling may feel like an outsider in the family.

2.8.6.1 Coping strategy:

In a variety of ways, family caregivers indicate their coping capacities. Coping efficacy can be reflected by indirect means, such as how families communicate with professionals (Lees, 1988). Tomberg et al., (2007) examined coping strategies, social support, and life orientation in those with moderate to severe **TBI** in relation to health related quality of life. Family adaptation and coping occurs immediately after a **TBI** as well as on an extended basis. Immediately after **TBI**, families often demonstrate a variety of *grief* reactions when trying to come to terms with the reality of the injury. Many families first experience *denial* of the outside of the immediate family system (Jacobs, 1989; McKinlay and Hickox, 1988). *Later grief* reactions can include depression, anger, and anxiety (Brooks, 1991). Muir and Haffey (1984) suggested that **TBI** family grief reactions occur in a similar manner as the *death grieving* model. However, they characterized **TBI** family grieving with the term, "mobile mourning" as the person with **TBI** may never fully regain pre-injury functional capacities. Subsequently, families can experience the grieving processes repeatedly.

After the acute injury stage, however, families faced the long-term reality of adapting to the family member's **TBI**. Family caregivers vary in their ability to *cope*

with this adjustment. On a long-term basis, differences in adaptation and coping efficacy are often functions of preinjury family characteristics (Wesolowski and Zencius, 1994) as well as the ability to reach out to coping resources.

2.9 Outcomes:

The severity of traumatic brain injury ranges from mild (a brief change in mental status or consciousness) to severe (an extended period of unconsciousness or amnesia after the injury). Traditionally, children have better outcomes than adults after **TBI** (Semth; 2005). Very young and preschool children have worse outcomes both in mortality and long-term disability than older children and adolescents (Adelson; 2000). CDC (2006) estimates that at least 5.3 million Americans currently have long-term or lifelong need for help to perform activities of daily living as a result of a **TBI**. Brain injury can causes a wide range of functional changes affecting thinking (memory and reasoning), sensation (touch, taste, and smell), language (communication, expression, and understanding), and emotion (depression, anxiety, personality changes, aggression, acting out, and social inappropriateness).

TBI can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age. About 75% of **TBIs** that occur each year are concussions or other forms of mild **TBI**. Repeated mild **TBIs** occurring over an extended period of time (hours, days, weeks, months, years) can result in cumulative neurological and cognitive deficits (Semth; 2005).

Impact of long term deficit on both **TBI** individuals and caregivers Families of people with **TBI** face numerous challenges and stresses in providing care. They face living with and providing care for a person that in many ways is different from the person he or she was before the injury. The injured family member may demonstrate a variety of physical and behavioral care needs that make family caregiving especially stressful and burdensome. As families have been increasingly recognized as the primary caregivers for people with **TBI**, varied research has investigated the extent of stress and burden family caregivers experience.

For **TBI** survivors, the pace of resuming former levels of physical activity is faster than that of resuming normal psychosocial functioning (Dikmen et al, 1993).

Some researchers have said the recovery of physical or cognitive status during the first 2 years after injury was most critical (Oddy et al, 1985). Millis and colleagues' study (2001) showed neuropsychological recovery might continue several years after injury with substantial recovery. Corrigan et al, (1998) stated that outcomes during the first 5 years after discharge were dynamic. Changes in **TBI** survivors noticeably influence the people who surround them, particularly their family members. These interactions occur in complex ways, given the unique structure of each family. Research on family stress after **TBI** indicated behavioral and personality changes were more burdensome than purely physical disabilities because emotional and cognitive disturbances tended to persist longer than physical disabilities (Brooks et al, 1986 and Oder et al, 1992). These disturbances included decreased memory, problems with decision-making, mood swings, and long-lasting emotional and physical dependency (Acorn, 1993). **TBI** individuals' behavioral symptoms (aggression, for example) usually increased over time as other indicators of functional disability decreased (Brooks et al, 1986). Consequently, families may perceive the **TBI** individuals as more of a burden as time passes.

2.9.1 TBI children and the school:

The cognitive deficit due to **TBI** may make it difficult to return to the same job or school setting the individual was in before the injury (Turner et al; 1997). While fewer focal deficits may be apparent, children appear to develop blunting across all areas of higher cognitive functioning. These deficits may not become apparent until later in the child's development. Children with **TBI** face difficulties because of impaired new learning, inability to take on social cues, and behavioural, educational and schooling problems. These problems pose difficulties for parents, teachers and healthcare workers. There may be a poor fit between the needs of children with **TBI**, and typical school educational programs. Parents are faced with many challenges, including coping with changed academic aspirations for their child. Souza and colleagues (2007) found that Children with **TBI** report significantly reduced Quality-of-life (QoL) compared to a control group in the physical, psychological, cognitive and total score dimensions. However, **TBI** children with average academic performance (65%) obtained the same QoL scores as the control group. Child with **TBI** requires special education services after discharge from medical center and readiness to retune to school may be particularly problematic due to social-behavioural challenges (Bedell et al; 2002).

2.9.2 Re-entry to work:

Ultimately, rehabilitation must take place in the community rather than the controlled environment of a rehabilitation facility. Some **TBI** individuals do best with individual therapy (speech, occupational, physical) at an outpatient facility or at home. For others, a multidisciplinary, case-managed program works best. This approach utilizes a team of professionals that is usually composed of one or more therapists and social workers, a case manager, and vocational specialist. Case-managed programs are very effective, especially for **TBI** with complex medical and social problems. Return to work is an important factor that contributes to satisfaction and quality of life. On first returning to the community, people with **TBI** may have reduced awareness of their cognitive deficits, and can fail or do badly if pressured to return to work, study or household responsibilities too soon. Vocational and leisure options may include retraining, rescaling, on-the-job training or supported employment services (Campbell; 2000).

Return to work after mild traumatic brain injury (**MTBI**): Following **MTBI**, a majority of individuals are able to resume normal work duties with little or no therapeutic intervention. A smaller percentage of individuals with **MTBI** have deficits, with functionally disabling consequences. Individuals with **MTBI** may be instructed to temporarily reduce the amount, type, and intensity of their work duties, or temporarily remain out of work entirely, depending on their clinical condition. Physicians should attempt to be clear and specific in documenting vocational restrictions, a plan for re-entry to work, and communication with the employer (for example, supervisor, safety officer, employee health nurse). For **TBI** individual with significant deficits, an interdisciplinary team approach may be recommended which can include a neuropsychological assessment, vocational evaluation and job site analysis, early contact with employer, assessment of vocational feasibility, supervisor education, transferable skills analysis, skillful increased titration of job duties and demands, job coaching, physical, occupational, and speech therapy, mental health services. For individual with **MTBI** who have persistent deficits, or who have difficulty once back at work, a return-to-work program should occur, which requires a carefully designed and managed plan by the **TBI** individuals, employer, and treatment team. Communication among all involved parties, and the avoidance of fragmentation among treatment professionals is critical to successful outcome. Following return-

to-work, maintenance support services are appropriate to best insure the durability of outcome (Stokes; 2004)

Return-to-Work Moderate-Severe **TBI**: Following Moderate-Severe **TBI**, many individuals are unable to return-to-work. Successful return-to-work among individuals with moderate-severe injury requires an interdisciplinary approach including neuropsychological assessment, functional capacity evaluation, job site analysis, early contact with employer, assessment of vocational feasibility, transferable skills analysis, supervisor education and coaching, coworker education, pre-vocational job trials, job placement, job education, skillful increased titration of job duties and demands, mental health and family counseling, and follow-up services (Cuccurullo; 2004). Johnstone and colleagues (2003) analyzed information collected from 35 people who experienced a **TBI**. Data about employment, income, and government assistance was gathered at the time of injury and one year later. The researchers concluded that after one year, the number of people who were working decreased by 55% and the number of people without jobs increased by 42.5%.

2.10 Disability and Islamic religion:

Allah has created people in different races, colors and having various abilities. While some of them are given certain gifts, others are deprived of these gifts and thus are disabled. This is the nature of life, according to the Divine Wisdom through which Allah governs everything.

It is also a great thing that Almighty Allah, when depriving a person of a certain ability or gift, compensates him for it, by bestowing upon him/her other gift, with which he excels others.

In order to be an active member in the society, a disabled person needs to be fully aware of his surroundings and the nature of his disability. In addition, it is incumbent on the society to offer a helping hand to all those people. Islamic history has a shining record of many examples of people who, while having some kind of disability, occupied very excellent positions and prominent status in the society.

It is the duty of the whole society to establish schools, place and all human rights for those persons and secure them due care so that they become good members of the society and that they benefit themselves and their families. It is duty of us Muslims to should the responsibility of showing the utmost care to those people, for,

according to the teachings of our religion, those persons are sources of Divine mercy and blessings being showered on us now and then.

2.11 Summary:

TBI is a devastating injury. Rehabilitation of **TBI** individuals is multidimensional. It is time consuming and needs collaboration of different endeavors in terms of rehabilitation team, community and decision makers. An important aspect is community inclusion. However, **TBI** individuals' community inclusion is of great importance to improve **TBI** individuals' life satisfaction and quality of life, it might involve troubles for care providers such as caregiver. This study is going to investigate this area. Chapter three is going to discuss available and related literature.

CHAPTER "3"

LITERATURE REVIEW

3.1 Introduction

3.1.1 Studies related to economic and psycho-social aspects,

3.1.2 Studies related to families caring **TBI** patients

3.1.3 Studies related to persistent disability

3.2 Summary

3.1 Introduction:

Relevant research to the current study topic will be presented in this chapter. That's includes studies related to economic and psycho-social aspects, studies related to families caring **TBI** patients and studies related to persistent disability. Researcher will discuss the relevant study as follows objectives, importance, sample size, statistical manipulation and results.

3.1.1 Studies Related To Economic And Psycho-Social Aspects:

Livingston et al (1985): Three Months After Severe Head Injury: Psychiatric And Social Impact On Relatives

Female relatives of defined groups of consecutive male minor and severe head injury victims were seen at home 3 months after the injury. The relatives of the severely injured suffered significant psychiatric morbidity compared to the minor head injury relatives. They also showed poorer functioning in social roles associated with the home. There was no difference in the vulnerability of either wives or mothers of the head injury victims. It is argued that there is a need for support for the relatives of those who have suffered severe brain injury.

Oddy et al (1985): Social Adjustment After Closed Head Injury: A Further Follow-Up Seven Years After Injury

A group of severely head injured patients were reassessed 7 years after injury. This group was the same as that previously reported 2 years after injury (Livingston et al, 1985). There was no change in their physical or cognitive status; personality problems were still commonly reported but the less disabled had made further progress in returning to their former level of vocational and social activity.

Dikmen et al; (1993): Psychosocial Outcome In Patients With Moderate To Severe Head Injury: 2-Year Follow-Up

Dikmen et al; (1993) used two groups (intervention and control group) to search out psychosocial outcome and recovery following the **TBI**. Intervention group was 31 adult patients with moderate to severe head injuries who were prospectively investigated over a 2-year period. A friend control group was used for comparison

purposes. Dikman et al; (1993) concluded that moderate and severe head injuries have a significant long-term impact on psychosocial functioning. More specifically, although there is an increase over time in the number of subjects who resume former levels of activity, many moderate to severely head-injured people remain unable to work, support themselves financially, live independently and participate in pre-injury leisure activities at least up to 2 years post-injury. Initially, self-perceived limitations in everyday functioning are widespread, with physical functioning being of primary concern. Over time, there is improvement in both physical and psychosocial areas. However, in spite of improvement, difficulties in psychosocial functioning become dominant later due to greater improvement in the physical area. This study gives no evidence of general increase in emotional distress with increasing time since injury.

Schalén et al (1994): Psychosocial Outcome 5-8 Years After Severe Traumatic Brain Lesions And The Impact Of Rehabilitation Services

Schalén et al (1994) addressed in their study three questions. First, what is the long-term psychosocial outcome for severely head-injured patients? Second, is an increased survival rate associated with an increase in the number of patients with a poor quality of life? Third, do rehabilitation services affect the final outcome? The researchers used the questionnaire for self-rating, interview with patients and relatives, Hopkins Symptom Checklist (HSCL; a Neurophysical examinations), Social Adjustment Scale--Self-Report (SAS--SR) and Comprehensive Psychopathological Rating Scale (CPRS). The researchers found that one hundred and six patients initially judged as good recovery/moderate disability (GR/MD) 6 months post-injury participated in the study. 40-50% of these patients showed co-ordination disturbances; more than 20% had speech disorders and cranial nerve deficits. 28% had psychiatric symptom scores on the Hopkins Symptom Checklist (HSCL) indicating need of treatment. Social function according to the Social Adjustment Scale--Self-Report (SAS--SR) showed that 40% had problems concerning interpersonal relations and 20-30% had problems within the field of leisure activities, but few problems were reported on work activities and economy. The Comprehensive Psychopathological Rating Scale (CPRS) revealed that hostile feelings, failing memory and fatigability were common symptoms and were reported by relatives in 71%, 52% and 48%, respectively, but the mean distress levels were moderate. A correlation was seen between quality of life reported

by relatives and the degree of mental and social disability according to the Bond Outcome Scale, but the correlation to neurophysical handicap was rather weak. The majority of patients were able to return to a productive social life. The proportion of patients with a poor long-term outcome did not increase after introduction of an aggressive management protocol for head injuries. Data indicated that improvements in facilities for rehabilitation may positively affect psychosocial adjustment.

Hall et al (1994): Family Stressors In Traumatic Brain Injury: A Two-Year Follow-Up

The aim of this longitudinal study was to investigate the relationship of family stress to a number of factors such as unemployment. Caregivers of 51 **TBI** inpatients were interviewed at rehabilitation admission and by phone at 6, 12, and 24 months postinjury. Caregivers reporting financial strain increased 22% from rehabilitation admission. Forty-seven percent of caregivers had altered or given up their jobs at 1 year postinjury, and 33% at 2 years postinjury.

Finset et al (1995): Self-Reported Social Networks And Interpersonal Support 2 Years After Severe Traumatic Brain Injury

Social interaction and support, subjective complaints, and functional status were assessed. The study sample included fifty-four patients with traumatic brain injury (**TBI**) consecutively admitted to a rehabilitation hospital were examined 2 years post-injury. Finset et al (1995) found that thirty-one patients (57.4%) reported that their social networks had markedly declined subsequent to injury.

Perlesz et al (2000): Psychological Distress And Family Satisfaction Following Traumatic Brain Injury: Injured Individuals And Their Primary, Secondary, And Tertiary Carers

Perlesz et al; (2000) compared two groups (intervention and control) to assess families following **TBI**. They used Beck depression inventory, State anxiety inventory and Profile mood state. Sample size was seventy-nine families (65 individuals with **TBI**, 72 primary carers, 43 secondary carers, and 22 tertiary carers) which were drawn from a sample of outpatients of three metropolitan, acute rehabilitation hospitals over a 12-month period. Perlesz et al; (2000) used multivariate analysis of variance (ANOVAs) and cross sectional design. Perlesz et al; (2000) found that there were

different levels of psychological distress and family satisfaction within families and significant proportion of carers were not psychologically distressed and TBI patients were more vulnerable to the risk of psychological distress than carers and wives of TBI patient were at greater risk of psychological distress than other carers such as father brother or mother. The majority of primary carers were females. Primary carers reported anger, fatigue, depression and anxiety and many families managed to cope well.

Kersel et al (2001): Psychosocial Functioning During The Year Following Severe Traumatic Brain Injury

Kersel et al (2001) assessed psychosocial functioning of a group of adults with severe traumatic brain injury at 6 months and 1 year post-injury. They investigated the aspects of emotional, behavioural, and social functioning. For this reason, they used a group of 65 adults with severe traumatic brain injury. Results were in agreement with previous studies (Finset et al, 1995; Oddy et al, 1985 and Livingston et al, 1985). The prevalence of depression remained constant (24%) over time, although there was some individual variation in the reporting of symptoms. Impatience was the most frequently reported behavioural problem at both assessments. Whilst there was a slight increase in the number of behavioural problems and level of distress reported over time, the most obvious change was in the type of behavioural problems that caused distress. At 1 year post-injury, problems with emotional control were found to be most distressing for the patients. A comparison with pre-morbid social functioning showed the loss of employment to be 70%, 30% returned to live with their parents, and relationship breakdown occurred for 38%. There was also a significant and ongoing decrease in all five aspects of social and leisure activities.

Ergh et al (2003): Social Support Moderates Caregiver Life Satisfaction Following Traumatic Brain Injury

Ergh et al (2003) examined the extent to which social support moderates the influence of characteristics of the person with injury on caregiver subjective well-being. Sixty pairs of individuals who had sustained a moderate to severe TBI and their caregivers (N=120) participated in this study. Cognitive, functional, and neurobehavioral functioning of participants with TBI were assessed using a

neuropsychological tests and a rating scale. While Caregiver life satisfaction and perceived social support were assessed using self-report questionnaires. The study findings showed that time since injury was unrelated to life satisfaction. Neurobehavioral disturbances showed an inverse relation with life satisfaction. Social support emerged as an important moderator of life satisfaction. Only among caregivers with low social support was cognitive dysfunction adversely related to life satisfaction. Similarly, a trend suggested that patient unawareness of deficit was associated with caregiver life dissatisfaction only among caregivers with low social support. In contrast, these characteristics were unrelated to life satisfaction among caregivers with adequate social support.

Serna and Sousa (2006): Changes In Social Roles: A Consequence Of Traumatic Brain Injury For The Family Caregiver

Serna and Sousa (2006) studied changes in the caregiver's social roles after traumatic brain injury (**TBI**), relating them with the degree of importance of these roles and with the condition of the victim six months or more after the **TBI**. A study sample of 50 caregivers and 50 victims of **TBI** were used. The data was collected by means of interview and patient file analysis. The researchers used a checklist which was built for the interview with the caregiver, in order to identify the changes and importance of their social roles. They found that roles that had suffered most interruption due to the trauma were: friend, amateur/entertainment, family member and worker. The role of being a caregiver was the one that presented more modification. No association was found between change of role and the variables: condition of victim after **TBI** and importance of the social roles for the caregiver.

Rivera et al (2007): Predictors Of Caregiver Depression Among Community-Residing Families Living With Traumatic Brain Injuries:

The study objective was to test the hypothesis that ineffective problem-solving abilities would be significantly predictive of risk for depression in caregivers of persons with traumatic brain injury (**TBI**) after controlling for caregiver burden, caregiver health and demographic characteristics. Rivera et al (2007) used Centers for Epidemiologic Studies - Depression scale (CES-D). The study sample included 57 women and 3 men caring for a relative with a **TBI**. The researchers used correlational

and logistic regression analyses of cross-sectional data. The main findings were as follows. Twenty-nine caregivers (48.3%) had CES-D scores that met the criteria for risk of depression. An ineffective approach to problem solving, characterized by negative, avoidant, and careless/impulsive styles, and self-reported caregiver physical symptoms were significantly predictive of caregiver depression regardless of length of time caregiving, perceived burden, or demographic variables. The researchers concluded that caregivers of persons with **TBI** who report physical health problems and who exhibit ineffective problem solving area are at greater risk for depression, regardless of the time they have spent in their role as a caregiver.

3.1.2 Studies Related To Families Caring TBI Patients:

Acorn (1993): Head-Injured Survivors: Caregivers And Support Groups

Carers of **TBI** survivors may experience a severe psychological distress; therefore, Acron (1993) assessed the needs of caregivers of head-injured survivors and the availability. For the reason of data collection, the researcher used a sample of **TBI** caregivers in which the majority is mothers. The study findings agree with Jumisko et al (2007) and Harris (2001) who suggest the need for additional support groups, especially in smaller communities, for additional educational content in support groups and for respite beds.

Resnick (1993): The Effect Of Head Injury On Family And Marital Stability

In this study, Resnick (1993) examined the way how **TBI** affects family and marital relationships. The researcher used a retrospective design and a questionnaire to collect the essential information to complete the study from relatives of head injured individuals. The researcher found that the implementation of a case-management system, incorporating significant roles and functions for social workers can assist families in coping with traumatic brain injury.

Kreutzer et al (1994): Primary Caregivers' Psychological Status And Family Functioning After Traumatic Brain Injury

Kreutzer et al. (1994) used a sample of 62 **TBI** patients' caregivers to investigate the prevalence of psychological distress and unhealthy family functioning among primary caregivers adult outpatients with traumatic brain injury. They used the Brief

Symptom Inventory (BSI) and the Family Assessment Device (FAD). Approximately half of the caregivers reported elevated distress as indicated by scores on the BSI General Stress Index. Elevations on the Anxiety scale were evident among one-third of the sample, and one-fourth demonstrated elevations on the Depression subscale. Elevated scores on the Paranoid Ideation and Psychoticism scales suggested that feelings of burden and alienation were commonly reported. Caregivers, as indicated by the FAD, showed greater levels of unhealthy functioning relative to published norms for non-patient and medical patient samples, but showed better functioning than psychiatric samples. Spouses were significantly more likely to report elevated depression scores compared to parents. There was also a trend for spouses to report greater unhealthy family functioning than parents. Findings of this study are in agreement with those reported by European researchers. Furthermore, experience indicates that the BSI and FAD are potentially valuable clinical and research tools.

Douglas et al (1996): Indicators Of Long-Term Family Functioning Following Severe Traumatic Brain Injury In Adults

This study investigated the degree of association between four sets of predictor variables (demographic, injury-related, patient functioning, and caregiver functioning variables) and the criterion variable of long-term family functioning following severe traumatic brain injury (TBI). In order to collect the necessary information for the present study, thirty families participated in the study and a minimum of 3.5 years had elapsed since the time of injury. Data collection took place in the family home and both the brain-injured family members and primary caregivers were involved. Standard regression analyses revealed that two sets of variables accounted for a significant amount of variance in long-term family functioning. The largest amount of variance, 55% (44% adjusted), was accounted for by the caregivers' self-report variables which measured caregivers' depression, social support, and coping as well as caregivers' perceptions of patient competency. Overall, measures of severity of injury (PTA), residual neurobehavioural function, and adequacy of social support for caregivers proved to be reliable and significant indicators of family functioning. These findings are discussed with respect to their implications for service delivery and long-term provision of support for caregivers of severely brain-injured individuals living with their families.

Kausar and Powell (1996): Coping And Psychological Distress In Carers Of Patients With Neurological Disorders

Kausar and Powell (1996) endeavored to examine the coping levels and psychological distress experienced by carers of patients with neurological disorders. The study sample included 112 carers (either a close relative or a friend) of patients. Ways of Coping Questionnaire, the Leeds' scales for anxiety and depression, and a 10 point rating scale were used to measure coping and subjective burden in carers. Data collection from carers took place 4-18 months after the onset of neurological disorders in the patients. The researchers used a hypothesis and data were analyzed using t-test analysis, correlation and regression analyses in order to answer the study hypothesis. The researchers found that carers experienced a great amount of psychological distress. Those carers who were more dependent on emotion-focused coping styles reported greater distress as compared to those who depended more on problem-focused strategies.

Leathem et al; (1996): Relatives' Perceptions Of Role Change, Social Support And Stress After Traumatic Brain Injury

Leathem et al; (1996) aimed to investigate the correlation between role change, social support and stress after TBI among parents and partners; therefore, they used a sample of 18 parents and 11 partners. The researchers used a single structured interview, including both verbally administered and written response questionnaires: the Daily Hassles and Uplifts Scale, the Arizona Social Support Interview Schedule and questions regarding role change and health problems. The combined parents and partners group indicated that they experienced moderate levels of stress and role change. A relatively small proportion of participants reported experiencing health problems. Partners indicated a slightly higher degree of stress and a greater degree of role change than parents, and a larger proportion of partners indicated the presence of health problems. There was little quantitative or qualitative difference between the two groups in sources, utilization of and satisfaction with social support. There was positive correlations between stress and role change and stress and health problems.

Olver et al (1996): Outcome Following Traumatic Brain Injury: A Comparison Between 2 And 5 Years After Injury

TBI individuals need a lifelong intervention. The researchers (Olver, et al; 1996), in this longitudinal study, assessed 254 traumatic brain injury (TBI) patients at 2 years and 103 at 5 years following discharge from a comprehensive rehabilitation

programme. They used a structured interview format detailing neurological symptoms, mobility, independence in ADL, productivity status, relationship issues, communication and the presence of cognitive, behavioural and emotional changes. The aim of this study was to examine long-term outcome in traumatically brain-injured individuals after discharge from a comprehensive rehabilitation programme. The researchers found that visual difficulties, headache and fatigue were persistent in a significant number of patients. Between 2 and 5 years there was increased independence in personal, domestic and community ADL and the use of transport. Moreover, ten more patients had returned to driving. Besides, there was a slightly higher incidence of cognitive, behavioural and emotional changes reported at 5 years. Thirty-two percent of those working at 2 years were not employed at 5 years. Many students had also become unemployed. These findings suggest the need for lifelong intervention following TBI. Rehabilitation systems should be adapted to provide this need.

Smith and Schwirian (1998): The Relationship Between Caregiver Burden And TBI Survivors' Cognition And Functional Ability After Discharge

This study explored new and different aspects of TBI. It investigated the impact of cognition and functional ability in adults with TBI on perceived caregiver burden. Therefore, the researchers used a sample of forty-two subjects with TBI and studied their caregivers during the follow-up clinic appointment 3 months after discharge from a 31-bed inpatient rehabilitation unit. The researchers used Pearson correlation and simple single regression statistical tests to examine the relationship between reported caregiver burden (as measured by the Burden Interview) and cognition and functional ability (as measured by the Functional Independence Measure instrument) of people who had experienced traumatic brain injury (TBI). Functional ability and cognition both negatively affected reported caregiver burden, although the relationship was not statistically significant.

Wade et al (1998): Family Burden And Adaptation During The Initial Year After Traumatic Brain Injury In Children

This study compared adverse consequences after "moderate and severe TBI" and orthopedic trauma amongst children. Wade et al (1998) used a sample which comprised 189 children between the ages of 6 and 12 whom were recruited from hospital trauma and inpatient units. The study sample included 53 children with severe

TBI, 56 children with moderate **TBI**, and 80 children with orthopedic injuries not involving central nervous system insult. Measures of injury-related burden, parental distress, and family functioning were used to collect the necessary data for the study from the child's primary caregiver at baseline assessment conducted soon after injury and at 6- and 12-month follow-ups. Multivariate repeated measures analysis of covariance was used to examine group differences in these outcomes over time. Caregivers of severe **TBI** children reported significantly higher levels of family burden, injury-related stress, and parental psychological symptoms than caregivers in the orthopedic injury children. The two groups did not differ with respect to marital distress. Caregivers in the severe **TBI** group were significantly more likely than caregivers in the orthopedic group to exceed the clinical cutoff on the Brief Symptom Inventory and to report clinically significant levels of family dysfunction at follow-up.

Wade et al (1998) concluded that severe **TBI** is a source of considerable caregiver morbidity, even when compared with other traumatic injuries due to the fact that they had persistent stress associated with the child's injury, as well as the reactions of other family members, and a relative risk of clinically significant psychological symptoms nearly twice that of the orthopedic comparison group. These findings highlight the need for interventions that facilitate family adaptation after pediatric **TBI**.

Harris (2001): Caregiver Depression Following Traumatic Brain Injury (TBI): A Consequence Of Adverse Effects On Family Members?

Caregiver support obtained from rehabilitation team may have important and positive impact in reducing caregiver depression after **TBI**. Harris (2001) used a factorial design to find out the possible factors moderating and mediating between carer depression and analogous stressors. Fifty-eight carers participated in the study. Data collection took place at 6 months, 1 year, 2 years, or 3 years following injury. Forty-six per cent of the variance in caregiver depression was accounted for by carers appraisal of adverse family effects and the interaction of adverse family effects and support effectiveness. These findings highlight the importance of supporting families as a whole in the rehabilitation of persons with **TBI**.

Kolakowsky-Hayner et al (2001): Long-Term Life Quality And Family Needs After Traumatic Brain Injury

In this endeavor, Kolakowsky-Hayner et al (2001) assessed the life quality and long-term family needs of caregivers of persons with brain injury. The participants in

the study were requested to complete the Virginia Traumatic Brain Injury Family Needs Assessment Survey. Participants were 57 caregivers of persons with traumatic brain injury who were at least 4 years after injury and who resided in Virginia. The average age of respondents was 19-82 years and their gender was primarily Caucasian females. Results indicated diminished life quality after injury. With regard to family needs, Health Information (51.43%) and Involvement with Care (47.93%) needs were most often rated as met. Instrumental Support (31.52%) and Professional Support (28.38%) needs were most often rated as not met. Family needs and support systems for those needs change over time. This investigation provides evidence that unmet family needs extend well beyond the acute setting and that caregiver life quality diminishes over time. The importance of appreciating long-term family needs and other life quality issues should not be underestimated.

Marsh et al (2002): Caregiver Burden During The Year Following Severe Traumatic Brain Injury

Marsh et al (2002) assessed the subjective and objective burden in fifty-two primary caregivers of **TBI** individuals with physical, cognitive, emotional, behavioral, and social dysfunction. **TBI** individuals had severe traumatic brain injury. Caregivers were assessed at 6-months and 1-year postinjury. Measurements were taken six and twelve months postinjury. At 6-months postinjury, approximately one third of caregivers reported clinically significant symptoms of anxiety and depression, and poor social adjustment. By 1-year postinjury, the prevalence of anxiety and depression remained the same, although only one-quarter continued to report poor social adjustment. Participants in the study showed some evidence of adaptation, as the frequency with which various types of objective burden were reported remained stable, while the distress caused by these decreased in the first year postinjury. It appears that the impact of physical impairment on **TBI** caregivers is comparatively short-lived and that caregivers learn some practical ways to manage the behavioral problems of the people with **TBI**. Marsh et al (2002) stated that the person with **TBI's** behavioral and cognitive problems, over time, begins to play a larger role in the level of distress experienced by the **TBI** caregiver. Marsh et al (2002) explained that the person with **TBI's** suffers social isolation that has a stable and consistent role in the experience of subjective burden for primary caregivers in the first year postinjury.

Sander et al (2003): Preinjury Emotional And Family Functioning In Caregivers Of Persons With Traumatic Brain Injury

It is of great importance to study the preinjury family functioning, emotional distress, and social support of caregivers of persons with traumatic brain injury (TBI). This study involved three Traumatic Brain Injury Model Systems centers' inpatient rehabilitation facilities. It comprised a large sample; one hundred ninety-one caregivers, primarily white and female, of persons with TBI and used the Brief Symptom Inventory, Family Assessment Device, Multidimensional Scale of Perceived Social Support, and history of medical and psychiatric illness. Main findings were that thirty-seven percent of caregivers indicated symptoms of emotional distress consistent with psychiatric diagnoses for the month before injury, whereas 27% reported a history of psychiatric or psychologic treatment at some point in the past. Between 25% and 33% of caregivers reported unhealthy family functioning in 1 or more areas for the month before injury. Persons with an annual income less than US dollars 10,000 reported less healthy preinjury family functioning. Caregivers reported good satisfaction with preinjury social support, and very few caregivers reported a history of substance abuse. The findings of this study are of great importance as a substantial proportion of caregivers reported emotional distress and/or unhealthy family functioning before injury. Such difficulties may make them more vulnerable to the stress associated with injury and result in greater coping difficulties

Hsueh-Fen et al (2004): Love And Load: The Lived Experience Of The Mother-Child Relationship Among Young Adult Traumatic Brain-Injured Survivors

Hsueh-Fen et al (2004) described the meaning of the experience of the relationship between young adult traumatic brain injury (TBI) survivors and their mothers. They used a phenomenological approach (qualitative design) to identify the essential elements of the experience of traumatic brain injury. Informant participants in the study were 9 males and 3 females who were at least 2 years post-TBI, and their mothers, who were their primary caregivers after the injury. The average age of TBI informants was 18 to 25 years. They had motor vehicle accident-induced injury. TBI individuals were able to participate in a verbal interview, comprehend and express. A main finding was that survivors' parents marital relationships were at risk.

Hanks et al (2007): Caregiving Appraisal After Traumatic Brain Injury: The Effects Of Functional Status, Coping Style, Social Support And Family Functioning

This study aimed to examine functional status, coping style, social support and family functioning with respect to both positive and negative appraisals of caregiving in four main areas: perceived burden, caregiving relationship satisfaction, beliefs about caregiving, and mastery with caregiving. For the reason of this study, the researchers used a sample of sixty primary caregivers of individuals who sustained a **TBI** within the last 6 months to 15 years. Furthermore, they used the Caregiver Appraisal Scale, the Coping Inventory for Stressful Situations, the Family Assessment Device, and the Social Provision Scale. The study findings were examined in relation to the **TBI** survivor's scores on the Disability Rating Scale and the Functional Independence Measure at the same time points post-injury. The study findings revealed that the majority of caregivers in those with moderate to severe brain injuries experienced dissatisfaction with many aspects of caregiving, especially with respect to feelings of burden and mastery. The study recommends that there is a need to develop interventions for caregivers of persons with **TBI**, especially with respect to coping style and social support networks.

Jumisko et al (2007): Living With Moderate Or Severe Traumatic Brain Injury: The Meaning Of Family Members' Experiences

A qualitative design and interview were employed in a group of eight family members by Jumisko et al (2007) to collect the necessary data and perform the current study. The researchers aimed to elucidate the meaning of family members' experiences of living with an individual with moderate or severe **TBI**. Data interpretation revealed that family members struggled with their own suffering while showing compassion for the injured person. Their willingness to assume care for the injured person is derived from their feeling of natural love and the ethical demand to be responsible for the other. Family members obtained strength from hope, natural love, close relatives, the afflicted person, and other family members. Jumisko et al (2007) agree with Harris (2001) that it is important that professionals should pay more attention to the suffering of close relatives and provide them with continuous support in different phases.

Rotondi et al (2007): A Qualitative Needs Assessment Of Persons Who Have Experienced Traumatic Brain Injury And Their Primary Family Caregivers

This study focuses on the needs of both **TBI** individuals and their primary caregivers. The researchers, in order to assess the respondents' needs, used a semistructured interview, a sample of 80 **TBI** individuals with an average time since their most severe **TBI** of 5.8 years, and 85 primary support persons. Respondents described their needs via phases that was parallel to transitions in settings, treatments, and responsibilities (for example, acute care, in-patient rehabilitation, return home, and living in the community). Prominent themes during in-patient phases included care provided quality, emotional support, and understanding the injuries. Prominent themes during return to community included guidance, life planning, community integration, and behavioral and emotional issues. Participants in the study reported insufficient education and preparation for the future. Current methods of identifying needs must be based on populations' perceptions and take in account the needs that occur over the course of treatment and rehabilitation. Services must meet the ongoing changes in needs, accessible to consumers of services and designed to be directed and customized by users.

Souza et al (2007): Quality-Of-Life: Child And Parent Perspectives Following Severe Traumatic Brain Injury

It is worthwhile to study the Quality-of-life (QoL) of children with **TBI** and compare the findings with the evaluations of parents and children without brain injury. Souza et al (2007) used a sample of 23 children with **TBI**, mean age 11 years, who had been treated at the SARAH Network of Rehabilitation Hospitals. In order to decrease bias in the study, the researchers used matching by age, sex, parents' socio-cultural level and place of residence with 23 other children who had no history of brain injury. The SARAH QoL Questionnaire for Children and Adolescents, Wechsler Intelligence Scale for Children, the SARAH Physical-Functional Classification of the Child and Adolescent and a structured interview with parents were used to collect the necessary information to perform the study. The results demonstrated that, in an average 4 years after the accident, all of the children with **TBI** were attending school and most could walk independently. The parents' reports about post-**TBI** problems were marginally associated with the children's self-evaluations. The parents showed important concerns

regarding their child across all dimensions of life. Children with **TBI** report significantly reduced QoL compared to a control group in the physical, psychological, cognitive and total score dimensions; however, **TBI** children with average academic performance (65%) obtained the same QoL scores as the control group.

Tomberg et al (2007): Changes In Coping Strategies, Social Support, Optimism And Health-Related Quality Of Life Following Traumatic Brain Injury: A Longitudinal Study

Tomberg et al (2007) aimed to identify changes in psychological coping strategies, social support, life orientation and health-related quality of life in the late period after traumatic brain injury (**TBI**). To collect the necessary data for this study, the researchers used a longitudinal design and thirty-one patients with **TBI** who were first investigated on average 2.3 years after injury and were prospectively followed on average 5.7 years later. In addition, the researchers used the Estonian versions of the COPE-D Test, the Brief Social Support Questionnaire, the Life Orientation Test and the RAND-36 questionnaire. During the late follow-up period, health-related quality of life and resuming work did not improve significantly. Persons with **TBI** reported an increase in seeking social/emotional support ($p<0.05$), frequent use of avoidance-oriented styles and reduced use of task-oriented styles. The study findings revealed that there are maladaptive changes in the profile of coping strategies and an increase in optimism. As social support, satisfaction with support and health-related quality of life did not improve, then rehabilitation, social and psychological support are continuously needed.

3.1.3 Studies Related To Persistent Disability Outcomes:

Brooks (1986): The Five Year Outcome Of Severe Blunt Head Injury: A Relative's View

In order to find out the outcome of severe **TBI**, Brooks (1986) used a sample of 42 severely injured **TBI** individuals. Close relatives of **TBI** individuals were interviewed at 5 years after injury, following initial study at 3, 6, and 12 months. Persisting severe deficits, in some cases worse than at 1 year, were primarily psychological and behavioural, although minor physical deficits, for example in vision, were also common. Relatives were under great strain; significantly more so than at 1

year. The best predictor of strain in the relative was the magnitude of behavioural and personality change in the patient.

Corrigan et al (1998): Outcomes In The First 5 Years After Traumatic Brain Injury

This study was conducted in an inpatient brain injury rehabilitation unit in a large Midwestern academic medical center and it aimed to examine the extent to which outcomes from **TBI** differ as a function of time and can be predicted at discharge from inpatient rehabilitation. Corrigan et al (1998) employed a survey method and cross-sectional analyses. Ninety-five **TBI** individuals, 6 months to 5 years after inpatient rehabilitation, stratified by time postdischarge. Functional Independence Measure (FIM), Sickness Impact Profile (SIP), Medical Outcomes Survey SF-36, Community Integration Questionnaire (CIQ), Craig Handicap Assessment and Reporting Technique (CHART), Brief Symptom Inventory (BSI), Satisfaction With Life Scale (SWLS), and indices of current psychosocial functioning were used to collect the necessary data to complete the study. Substance abuse, need for supervision, life satisfaction, and selected subscales of the CIQ and CHART differed over the period 6 months to 5 years after discharge. Approximately 75% of the variance in current FIM scores, and 40% to 50% of CHART, CIQ, and SIP total scores, could be predicted at time of discharge. Outcomes over the first 5 years after discharge were dynamic, with most change being improvement, at least after the first 2 years. Important aspects of outcome could not be predicted based on premorbid characteristics, injury severity, and initial functional abilities.

Gofin and Avitzour (2007): Outcome Of Head And Other Injuries Among Israeli Children: Physical Limitations And Stress Symptoms

Gofin and Avitzour (2007) conducted this study in Israel using a sample of 792 **TBI** individuals (Jews and Arabs aged 0-17 years old) with the aim to investigate the outcome of head and other injuries caused by diverse mechanisms and of varied severity. Participants (with the injuries) in the study were hospitalized for injuries in six hospitals in Israel. Caregivers were interviewed during hospitalization regarding circumstances of the injury and sociodemographic variables. Information on injury mechanism, profile and severity, and length of hospitalization was gathered from the medical files. Five months post-injury the caregivers were interviewed by phone

regarding physical limitations and stress symptoms. Head injuries occurred in 60% of the children, and of these, 22.2% suffered **TBI** with loss of consciousness. Among the rest, 22% of Jewish children and 28% of Arab children remained with at least one activity limitation, and no statistically significant differences were found among those with head or other injuries. The odds ratio for at least two stress symptoms was higher for children involved in transport-related injuries (OR 2.70, 95% confidence interval 1.38-5.28) than for other mechanisms, controlling for injury profile. No association was found between stress symptoms and injury severity. The researcher in this study concluded that most children had recovered by 5 months after the injury. Residual activity limitations were not different between those with head or with other injuries. Stress symptoms were related to transport-related injuries, but not to the presence of **TBI** or injury severity.

3.2 Summary:

Many studies were conducted over the last twenty-four years to investigate different aspects of **TBI** such as the economic and psycho-social impact of **TBI**, families caring **TBI** individuals and persistent **TBI** disability outcomes. The researchers used different samples such as **TBI** individuals, **TBIs'** caregivers, or both. The samples used were moderate to large. The results and conclusions were significant and related to this study. **TBI** has dramatic impact on client, caregivers and families. The researcher think that the endeavors of **TBI** related researches are well-directed.

CHAPTER "4"

METHODOLOGY

- 4.1 Introduction**
- 4.2 Research Design and procedures**
- 4.3 Research Setting**
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4.1 Introduction:

This chapter describes the methodology that was used in this research. The adopted methodology to accomplish this study uses the following techniques: the information about the research design, population, sample size and sampling, research setting, questionnaire design, statistical data analysis and content validity and pilot study.

4.2 Research design and procedures:

The researcher used an analytic descriptive design. The first phase of the research thesis proposal included identifying and defining the problems and establishment objective of the study and development research plan. The second phase of the research included a summary of the comprehensive literature review. The third phase of the research included a field survey which was conducted with the Functional Independence measurement (FIM), Disability Rating Scale (DRS) and Community Integration questionnaire (CIQ) were collected during the field survey. The fourth phase of the research focused on the modification of the questionnaire design, through distributing the questionnaire to pilot study. The purpose of the pilot study was to test and prove that the questionnaire questions are clear to be answered in a way that help to achieve the target of the study. In addition, it was important to ensure that all information received from samples would be useful in achieving the research objective. The questionnaire was modified based on the results of the pilot study.

The fifth phase of the research focused on distributing questionnaire. This questionnaire was used to collect the required data in order to achieve the research objective. The sixth phase of the research was data analysis and discussion. Statistical Package for the Social Sciences, (SPSS) was used to perform the required analysis. The final phase includes the conclusions and recommendations.

4.3 Research setting:

The study was conducted in the Gaza Strip: Northern of Gaza, Gaza City, Middle Zone, Khanyounis and Rafah. The fieldwork – data collection – took place between July 1st and August 1st 2007.

4.4 Research population:

The study population was all **TBI** individuals caregivers who were discharged from "El Wafa Rehabilitation Hospital and Specialized Surgery" in the period between 2000-2007 in the Gaza Strip (GS) which is a narrow piece of land lying on the coast of the Mediterranean Sea. Its position lies on the crossroads from Africa to Asia which made it a target for occupiers and conquerors over the centuries. Gaza Strip a very crowded place with area 365sq/km. The population is mainly concentrated in the cities, small villages and refugee camps which contain two thirds of the population.

The mid year population size of the Palestine in 2005 is estimated at 3.7 million. Out of total number 2.3 million in West Bank and 1.3 million in Gaza Strip with percentage (63%) and (37%) respectively.

In Gaza Strip, the population size is estimated at 1,389,789 (37.5%) of total population in Palestine. Out of which 703,532 (50.6%) are males and 686,257 (49.3%) constitutes (41.4%) of all Palestinian people overall the world including those in Diaspora, which is estimated at 7,968,543 (Palestinian National Authority 'PNA', 2005).

Population density in Gaza Strip is very high compared with the density in West Bank and the neighboring countries, Density rate is about 3,808 inhabitants per one square kilometer in Gaza Strip, and about 420 inhabitants per one square kilometer in West Bank. Actually, it must be taken into consideration that a sizeable area of the Gaza Strip and the West Bank is still occupied by Israeli settlers. Therefore, the actual density rates are higher than the estimated figures (PNA, 2005).

Age distribution of population has important implications on the health status of the population, due to the different health needs, the differential patterns of health care utilization and the different health status among the various age groups. Population pyramid shows age and sex distribution of population, (46.3%) is under 15 years. This pattern is more pronounced in the Gaza Strip, where (49.1%) are under 15 years. The age group under five years old still constitutes the largest proportion with a percentage of 18.3% of population (19.6% in GS). The ages 65 years and over constitutes (2.8%) of population, (2.5% in GS). Up to the age 40-44 years, there is gender predominance toward males, in age group of 45-49 years there is no gender predominance. Then after, gender is more predominance towards females (PNA, 2005).

Dependency ratio is calculated as the number of persons below fifteen and above sixty – five per 100 persons aged of 15-64 years. In 2005 the dependency ratio in Palestine dropped from 0.97 in 2004 to 0.96 in 2005. This does not reflect actual economic dependency in Palestine because not all people enrolled in the workforce age of 15-64 years is actually earning as students, housewives and unemployed persons (PNA, 2005).

As in most countries, the life expectancy at birth 2005 for women is higher than for men (72.3 Vs 71.2 years) (PNA, 2005).

Health Services In Gaza Strip:

Over the past year, the Palestinian health care system has been developing side by side with the development of Palestinian society in general. The ministry of health (MOH) is working with other health sectors in providing the primary health services mainly with United Relief and Work Agency for Palestinian Refugees (UNRWA), and Non Governmental Organization (NGOs) sector. At the end of 2005, there are 654 primary health care (PHC) centers in Palestine; these centers are cared for about 3.7 million people (129 centers in Gaza and 525 centers in West Bank). The total number of PHC centers in the Gaza Strip is 56 in comparison with 43 centers in 2000, with an increase of 30.2%. PHC system in Gaza Strip is well established and functioning despite the high population density and the overcrowding of population.

El Wafa Medical rehabilitation and Specialized Surgery (EWMRSSH):

Al-Wafa Nursing Home for the Elderly was established in 1980. The Home offers free social, health and recreational services. 30 people now reside there. The target group is the elderly poor of both sexes who have nobody to take care of them. The Home serves all of the Gaza Strip. It is non-stock, non-profit Palestinian NGOs, established in 1996 to offer medical rehabilitation services of cases recovering from post acute and chronic physical and cognitive disabilities through in and out patient departments. Rehabilitation team in the hospital includes rehabilitation doctors, nurses, physiotherapists, occupational therapists, speech communicational therapists and psychologists. El – Wafa hospital is the first and only nationally recognized inpatient rehabilitation hospital in Gaza Strip and it only includes 51 beds which are divided into 23 beds in female department (10 beds are allocated for children) and 28 beds in the male department.

4.5 Sample size and sampling:

Inquiry of the medical secretary in El- Wafa medical rehabilitation hospital showed that traumatic brain injury individuals who were admitted from 2000 to 2007 and have age below 69 years old to be 130 individuals. Due to time, cost and convenience, the researcher will use convenience sample to conduct this study.

In convenience sampling, a small sample can be used and is typically readily available. A sample of convenience has advantages and disadvantages. The researcher agrees with Indrayan and Sarmukaddam (2001); Blumenthal and Diclemente (2004) that the sample of convenience reduces cost, saves time, and increase the co-operation of the individuals who agree to participate in the study. Katzenellenbogen et al (1991); stress the importance of representative sample which ensures good quality information is obtained and reflects the population of the study and the ability to generalize sample results to all population. In order to improve the sampling strategy used in the study, convenience sample, the researcher will implement appropriate inclusion and exclusion criteria.

4.5.1 Inclusion criteria:

The study has the following inclusion criteria:

- The study includes both genders, male and female, caregivers of TBI individuals. The age of caregivers ranges from 18 to 50 years old.
- Participant caregivers in the study are free from sever medical problem or disability that may interact with disability burden.
- The TBI individuals who receive care from the above caregivers are home residents and they were discharged from a rehabilitation hospital before six months as minimum.
- TBI individuals who receive care are below (69) years old to avoid the interaction of chronic diseases such as DM, HTN, osteoarthritis and Parkinsonism.

4.5.2 Exclusion criteria:

- Caregivers who have disease or disability.
- Caregivers who provide care to TBI individuals with chronic disease such as DM, HTN and Alzheimer disease.

4.5.3 Ethical consideration and procedures:

Autonomy of participation and confidentiality of information will be assured. An approval to conduct the study was obtained from relevant research committee in the Islamic University in Gaza Strip. Consent form was given to every individual in the sample.

4.6 Data collection:

The researcher, in order to collect the required information, translated into Arabic and piloted the Disability Rating Scale (DRS), Community Integration questionnaire (CIQ) and Functional Independence measurement (FIM). She measured the validity and reliability of the translated instruments after collecting the data from participants in the pilot study.

4.6.1 Method of data collection:

Data collection has been done by four well-trained research assistants (qualified physiotherapist, BSc and nurse). The research assistants have received appropriate training on the way how to approach participants, ask questions and record the data. During filling of the study questionnaire the research assistants have read the questions in Arabic to the participants in the study and write down their answers according to each question. The community integration questionnaire (CIQ) has been completed according to the date obtained from the caregivers of **TBI** individuals. The disability rating scale (DRS) and the functional independence measurement (FIM) have been completed according to the date obtained from the **TBI** individuals.

The Functional Independence Measurement (FIM) is an 18-item 7-level functional assessment designed to evaluate the amount of assistance required by a person with a disability to perform basic life activities safely and effectively. It can be completed in approximately **22-30** min. A seven points scale is used to measure performance indifferent items where 1 mean totally dependant and 7 mean totally independent. The minimum score on the FIM is 18 the maximum score is 126 (Dittmar, et al;1997).

Disability Rating Scale (DRS) was designed to provide information regarding the progress of sever head injury. It has **8** items in four categories. The maximum score

can obtain on the DRS is 29 (extreme vegetative state). A person without disability would score zero. The DRS takes **5-15** min to be completed and can be done through phone interview (Dittmar et al; 1997).

Community Integration Questionnaire (CIQ): It is a measure of community integration after traumatic brain injury. The CIQ is a self-report questionnaire with **15** questions regarding community integration skills such as, shopping, home management, social integration, finances, leisure and productive activities. It was intended to be a brief and reliable measure of an individual integration into the home and community. The overall score, which represents a summation of the scores from individual questions, can range from **0 to 29**. A higher score indicates greater integration, and a lower score reflects less integration (Dittmar, et al; 1997).

4.7 Validity & Reliability:

It is customary practice that the survey instrument should be piloted to measure its validity and reliability and test the collected data. The pilot study was conducted by distributing the prepared questionnaire to panels of experts having experience in the same field of the research to have their remarks on the questionnaire.

Ten experts representing two panels were contacted to assess the questionnaire validity. The first panel, which consisted of eight expert doctors in Islamic university, was asked to verify the validity of the questionnaire topics and its relevance to the research objective. The second panel, which consisted of two experts in statistics, was asked to identify that the instrument used was valid statistically and that the questionnaire was designed well enough to provide relations and tests among variables.

Experts comments and suggestions were collected and evaluated carefully. All the suggested comments and modifications were discussed with the study's supervisor before taking them into consideration. At the end of this process, some minor changes, modifications and additions were introduced to the questions and the final questionnaire was constructed.

4.7.1 Initial questionnaire:

The researcher, initially, translated the original English questionnaires (DRS, FIM and CIQ), and accredited them by well-known ten expertise researchers. The researcher sent away ten Arabic questionnaires to the mentioned expertise and received

nine Arabic questionnaires (90%) with expertise' comments and changes. Accreditation by expertise people took place in (9/6 – 20/6/2007).

Table No. (1)
Schedule illustrate agreement rate

ITEMS NO.	AGREEMENT RATE	ITEMS NO.	AGREEMENT RATE	ITEMS NO.	AGREEMENT RATE	ITEMS NO.	AGREEMENT RATE
06	8/9=88.8	050	8/9=88.8	120	8/9=88.8	134	8/9=88.8
013	6/9=66.6	052	8/9=88.8	121	8/9=88.8	135	8/9=88.8
022	8/9=88.8	054	8/9=88.8	123	8/9=88.8	136	8/9=88.8
029	7/9=77.7	057	8/9=88.8	124	8/9=88.8	137	8/9=88.8
037	8/9=88.8	064	5/9=55.5	125	8/9=88.8	138	8/9=88.8
038	7/9=77.7	070	6/9=66.6	129	7/9=77.7	157	8/9=88.8
040	8/9=88.8	094	8/9=88.8	130	7/9=77.7		
043	7/9=77.7	105	8/9=88.8	131	7/9=77.7		
044	8/9=88.8	113	7/9=77.7	132	8/9=88.8		
047	7/9=77.7	114	7/9=77.7	133	8/9=88.8		

NOTE:

*The remain items, agreement rate equal 100%

*the agreement rate = 83.9%

The researcher reviewed and categorized the recommended changes. Two respondents (2/9) suggested to adding the study objectives in the covering letters. Four respondents (4/9) commented that face validity of the questionnaires must be improved such as using one numbering style and bold box where appropriate.

All comments and changes were treated as necessary to produce the version of the pilot questionnaire. In the **FIM**, one respondent (1/9) suggested adding one more word "assistive" in scoring key (second level). The average agreement rate was calculated as **97%**. Relevant to the **DRS**, two respondents (2/9) suggested adding one more words to clarify meaning in the personal data in DRS and last subheading. The average agreement rate in the DRS was calculated as **85%**.

The researcher, in the **CIQ**, replaced the term "retired" by the term "60 years old", changed the key scores from pointing to numbering style in FIM and gave code numbers to the completed questionnaires (01 to 09) to facilitate data entry on the computer and statistical analysis. Children's institute (2004: 18) defines childhood as the age from birth to 18 years; therefore, the researcher redefined the childhood age by age under 18 years old instead of age under 17 years old (CIQ: question 4). One respondent (1/9) suggested adding more words to clarify meaning in question seven (CIQ). Two respondents (2/9) suggested rewriting questions twelve and thirteen (CIQ) to improve sentence structure. The average agreement rate in the CIQ was calculated as **69.5%**.

There were twenty-seven dictation errors: two in the FIM (item one and third-sub heading); nine in the DRS (items tow, three, six, eight, nine, eleven, twelve and seventeen); and sixteen in the CIQ (items nineteen, twenty, twenty two, twenty three, twenty four, twenty eight, twenty nine, thirty, thirty one, thirty tow, thirty three, thirty four, thirty five, thirty six, thirty seven and forty eight). The average agreement rate between all items was found to be high (83.9%).

4.7.2 Piloting phase

Table No. (2)
Feedback on the pilot questionnaire
(N=30)

Zone	Rafah	Khnyonis	Middle zone	Gaza city	North Gaza	Total
Individuals	2 (16.6%)	7 (12.5%)	5 (16%)	12 (12.7%)	4 (11.1%)	30
Males %	1	5	3	8	2	19 63.3%
Females %	1	2	2	4	2	11 36.7%
Respondents %	2	5	4	7	2	20 66.7%
Non-respondents %	Zero	2	1	5	2	10 33.3%

In the following step, the researcher piloted the Arabic questionnaire by a small sample of **30** caregivers and refined it according to feedbacks. In order to reduce bias in

the piloting study, the researcher used different strategies. The individuals of the pilot sample (30 caregivers) were selected randomly as the **TBI** individuals from El Wafa Medical rehabilitation and Specialized Surgery (EWMRSSH) list of **TBI** individuals for the period 2000-2007. The researcher selected strata (equal proportions) from each zone and matched gender and age as well.

In order to perform the pilot phase, the researcher employed four research assistants, three physiotherapists and one nurse. These research assistants were given information about study topic and objectives and received relevant training to communication skills, questionnaire filling, notifying important information and keeping effective communication with the researcher. Training was done by Mr. Moussa Abu Mostafa (Master of occupational therapy) and Miss Amani Mezher (BSc of physiotherapy).

The researcher and research assistants visited thirty individuals (pilot study sample) to complete pilot questionnaires. Response rate was high (66.7%). Ten individuals (33.3%) were excluded due to blindness (10%), mental retardation (10%), death (40%), age of caregiver over 50 years (10%), diabetes mellitus (20%) and spinal cord injury (10%). The pilot study was performed in 23 - 28/6/2007.

To achieve the research goal, the researcher used the SPSS for manipulating and analyzing the data: Frequencies and Percentage; Cronbach's Alfa Test for measuring reliability of the items of the questionnaires; Person correlation coefficients for measuring validity of the items of the questionnaires; Spearman –Brown Coefficient; and One way ANOVA.

Validity refers to the degree to which an instrument measures what it is supposed to be measuring (Polit and Beck; 2004). Validity has a number of different aspects and assessment approaches. There are two ways to evaluate instrument validity: content validity and statistical validity, which include criterion-related validity and construct validity.

Content validity test was conducted by consulting two groups of experts. The first was requested to evaluate and identify whether the questions agreed with the scope of the items and the extent to which these items reflect the concept of the research problem. The other was requested to evaluate that the instrument used is valid statistically and that the questionnaire was designed well enough to provide relations and tests between variables. The two groups of experts did agree that the questionnaire

was valid and suitable enough to measure the concept of interest with some amendments (Polit and Beck; 2004).

To insure the validity of the questionnaire, two statistical tests should be applied. The first test is Criterion-related validity test (person test) which measure the correlation coefficient between each item in the field and the whole field. The second test is structure validity test (person test) that used to test the validity of the questionnaire structure by testing the validity of each field and the validity of the whole questionnaire. It measures the correlation coefficient between one filed and all the fields of the questionnaire that have the same level of similar scale (Polit and Beck; 2004).

Internal consistency of the questionnaire is measured by finding the correlation coefficients between each paragraph in one field and the whole filed. Tables below (3-5) shows the correlation coefficient and p-value for each field items. As show in the table the P- Values are less than 0.05 or 0.01, so the correlation coefficients of this field are significant at $\alpha = 0.01$ or $\alpha = 0.05$, so it can be said that the paragraphs of this field are consistent and valid to be measure what it was set for.

The **reliability** of an instrument is the degree of consistency which measures the attribute; it is supposed to be measuring. The less variation an instrument produces in repeated measurements of an attribute, the higher its reliability. Reliability can be equated with the stability, consistency, or dependability of a measuring tool. The test is repeated to the same sample of people on two occasions and then compares the scores obtained by computing a reliability coefficient (Polit and Beck; 2004).

It is difficult to return the scouting sample of the questionnaire that is used to measure the questionnaire validity to the same respondents due to the different work conditions to this sample. Therefore two tests can be applied to the scouting sample in order to measure the consistency of the questionnaire. The first test is the Half Split Method and the second is Cronbach's Coefficient Alpha.

This method depends on finding **Pearson correlation coefficient** between the means of odd rank questions and even rank questions of each field of the questionnaire. Then, correcting the Pearson correlation coefficients can be done by using Spearman Brown correlation coefficient of correction. The corrected correlation coefficient (consistency coefficient) is computed according to the following equation the correlation coefficient between each paragraph in the field and the whole field.

Table No. (3)

The correlation coefficient between each paragraph in the field and the whole Field (Functional independence measure(FIM))

Item no.	Item	Correlation coefficient	p-value
<u>Self-Care</u>			
A.	Eating	0.84	0.000
B.	Grooming	0.91	0.000
C.	Bathing	0.92	0.000
D.	Dressing-upper body	0.89	0.000
E.	Dressing-lower body	0.92	0.000
F.	Toileting	0.95	0.000
<u>Sphincter control</u>			
G.	Bladder management	0.820	0.000
H.	Bowel management	0.54	0.014
<u>Transfers</u>			
I.	Bed, chair, wheelchair	0.88	0.000
J.	Toilet	0.88	0.000
K.	Tub, shower	0.88	0.000
<u>Locomotion</u>			
L.	Walk/ wheelchair	0.85	0.000
M.	Stairs	0.93	0.000
<u>Motor subtotal score</u>			
.N	Comprehension	0.91	0.000
O.	Expression	0.55	0.023
<u>Social cognition</u>			
P.	Social interaction	0.65	0.002
Q.	Problem solving	0.56	0.009
R.	Memory	0.89	0.000

As revealed from this **table (3)** the correlation coefficient for every item of Questionnaire statically function, and the strongest one is (F = 0.95) and lowest one is (H= 0.54). So the items of questionnaire is statically function $\alpha = 0.01$.

Table No. (4)
The correlation coefficient between each paragraph in the field and the whole Field (Disability Rating Scale (DRS))

Category	Items No	Item	Coefficient correlation	p-value
Arousability, Awareness and Responsivity	(1)	Eye Opening	0.81	0.000
	(2)	Communication Ability	0.74	0.000
	(3)	Motor Response	0.73	0.000
Cognitive Ability for Self Care Activities	(4)	Feeding	0.81	0.000
	(5)	Toileting	0.91	0.000
	(6)	Grooming	0.86	0.000
Dependence on Others	(7)	Level of Functioning	0.92	0.000
Psychosocial Adaptability	(8)	Employability	0.73	0.000

As revealed from this **table (4)** the correlation coefficient for every items of Questionnaire statically function , and the strongest one is (7= 0.92) and lowest one is (3 = 0. 73). So the items of Questionnaire is statically function $\alpha = 0.01$.

Table No. (5)
The Correlation Coefficient Between Each Paragraph In The Field And The Whole Field (Community Integration Questionnaire (CIQ))

Item NO.	Item	Coefficient correlation	p-value
(1)	Who usually does the shopping for groceries or other necessities in your household?	0.72	0.000
(2)	Who usually prepares meals in your household?	0.63	0.003
(3)	In your home who usually does the everyday housework?	0.63	0.003
(4)	Who usually cares for the children in your home?	0.45	0.045
(5)	Who usually plans social arrangements such as get-togethers with family and friends?	0.47	0.035
(6)	Who usually looks after your personal finances, such as banking or paying bills?	0.63	0.003
(7)	Approximately how many times a month do you usually participate in shopping <i>outside</i> your home?	0.81	0.000
(8)	Approximately how many times a month do you usually participate in leisure activities such as movies, 9sports, restaurants, etc.	0.73	0.000
(9)	Approximately how many times a month do you usually visit your friends or relatives?	0.91	0.000
(10)	When you participate in leisure activities do you usually do this alone or with others?	0.74	0.000
(11)	Do you have a best friend with whom you confide?	0.46	0.045
(12)	How often do you travel outside the home?	0.48	0.031
(13)	Please choose the answer that best corresponds to your current (during the past month) work situation: m	0.46	0.040
(14)	Please choose the answer that best corresponds to your current (during the past month) school or training program situation:	0.53	0.016
(15)	In the past month, how often did you engage in volunteer activities?	0.73	0.000

As revealed from this **table (5)** the correlation coefficient for every items of Questionnaire statically function , and the strongest one is(9= 0.91) and lowest one is (4 = 0.45). So the items of Questionnaire is statically function $\alpha = 0.01$.

Table (6)
Split-Half Coefficient method

Section	Criteria	person-correlation	Spearman-Brown Coefficient	P-Value
(1)	Functional Independence Measure: (FIM)	0.7119	0.831707	0.000
(2)	Disability Rating Scale (DRS)	0.8154	0.898314	0.000
(3)	Community Integration Scale (CIQ)	0.8045	0.89166	0.000
	Total	0.8574	0.923226	0.000

Consistency coefficient = $2r/(r+1)$, where r is the Pearson correlation coefficient. The normal range of corrected correlation coefficient ($2r/ r+1$) is between 0.0 and + 1.0 As shown in Table (4), all the corrected correlation coefficients values are between 0.831707 and 0.89166 and the significant (α) is less than 0.05 so all the corrected correlation coefficients are significance at $\alpha = 0.05$. It can be said that according to the Half Split method, the dispute causes group are reliable.

4.7.3 Cronbach's Coefficient Alpha:

This method is used to measure the reliability of the questionnaire between each field and the mean of the whole fields of the questionnaire (Polit and Beck; 2004). The normal range of Cronbach's coefficient alpha value between - 1.0 and + 1.0, and the higher values reflects a higher degree of internal consistency. As shown in table (7) the Cronbach's coefficient alpha was calculated for the first field of the Functional Independence Measurement (FIM), the second field of Disability Rating Scale (DRS) and the third field of the Community Integration Scale (CIQ). The results were in the range from 0.7819 and 0.9580. This range is considered high; the result ensures the reliability of the questionnaire.

Table (7)
Cronbach's Alpha for Reliability

Section	Criteria	No. of Items	Cronbach's Alpha
1	Functional Independence Measure: FIM	18	0.7819
2	Disability Rating Scale (DRS)	8	0.8207
3	Community Integration Scale (CIQ)	15	0.9580
Total		41	0.8162

After collecting of the completed pilot questionnaires, there were few comments regarding the pilot questionnaire version. The researcher categorized and made all the recommended changes. More input in the 2nd page included **TBI** individual's data, caregiver data, research assistants name and date of completing questionnaire were added. A space in the last page was left to allow for research assistants comments. The researcher made a SPSS spread sheet (Statistical Package for the Social Sciences) for the data and entered the data on the computer. All the completed pilot questionnaires were used to perform the statistical analysis of the pilot study (20 questionnaires). One of the study leaders (Dr. Atef El-Agha) did the statistical analysis (r_1 FIM=0.78, r_2 DRS=0.82, r_3 CIQ=0.96)

4.8 Final questionnaire:

The study questionnaire consists of thirteen pages. The first page is a covering letter and consent form. The second page involves questions about biographical data related to **TBI** individual and their caregivers. Functional independence measurement (FIM) contains 18 items and it falls in page three. In next three pages, 4-6, Disability Rating Scale (DRS) is allocated and it contains 8 items. The last part is Community Integration Questionnaire (CIQ) which contains 15 questions distributed in four pages and guidelines how to fulfill the CIQ in two pages. The last page thirteen is for further comments and information.

4.8.1 Statistical analysis:

The researcher used the same spreadsheet used in the pilot study. The research assistants completed 100 study questionnaires out of 130 (76.9%) in which the participants met the study inclusion criteria. The response rate was high (100%). Thirty individuals did not meet the inclusion criteria and met the exclusion criteria.

The researcher used 100 questionnaires to perform the statistical analysis. Initially, the questionnaires were reviewed for incomplete or invalid answers and then were given code numbers (001-100). She entered the data on the computer. A peer randomly checked the data. A statistician did data statistical analysis by using (SPSS).

CHAPTER "5"

RESULTS

5.1 Introduction

5.2 Sociodemographic characteristics of study sample

5.3 Scales used in the study

5.3.1 Functional Independence Measurement (FIM)

5.3.2 Disability Rating Scale (DRS)

5.3.3 Community Integration Questionnaire (CIQ)

5.4 Correlations between scales

5.1 Introduction:

The researcher used the SPSS to perform statistical analysis. Descriptive statistic such as means, percentages and frequencies, and statistical tests such as spearman correlation coefficient and Eta test correlation were used to analyze the data collected and answer the research questions.

5.2 Sociodemographic characteristics of study sample:

Table No. (8)
Age distribution of participants in years
(N= 100)

Age	Frequency (%)	
1-10 years	Male	16 (16%)
	Female	6 (6%)
	22 (22%)	
11-20 years	Male	31 (31%)
	Female	13 (13%)
	44 (44%)	
21-30 years	Male	21(21%)
	Female	1 (1%)
	22 (22%)	
More than 30 years	Male	9 (9%)
	Female	3 (3%)
	12 (12%)	
Total	100 (100%)	

The average age of **TBI** individuals receiving care from participant caregivers in the study is 18.5 years. The majority of **TBI** individuals (44%) were 11-20 years old while the minority were 30 years old or above. 22% of **TBI** individuals were children (1-10 years old). While another 22% were young adults (21-30 years old). Children who are 1-18 years old are 60 **TBIs** (60%).

Table No. (9)
Type of TBI gender participants in the sample
(N= 100)

Gender	Frequency (%)
Male	77 (77%)
Female	23 (23%)
Total	100 (100%)

The great majority of TBI individuals in the study (77%) were male while females formed 23%.

Table No. (10)
Distribution of Participants in the zone
(N= 100)

Area	Frequency(%)
Gaza	47(%)
Khanyonus	21(%)
Middle zone	16(%)
North of Gaza	10(%)
Rafah	6(%)
Total	100(%)

Forty seven percent, majority of TBI patents, were form Gaza city while a minority (6%)where form Rafah. Khanyonus(21%), Middle zone(16%) and North of Gaza(10%).

Table No. (11)
Cause * Age Cross tabulation
(N= 100)

CAUSE	Categories	Statistics	AGE				Total	
			1-10 years	11-20 years	21-30 years	more than 30 years		
CAUSE	Road Traffic Accident	Count	14	35	7	5	61	
		% of Total	14.0%	35.0%	7.0%	5.0%	61.0%	
	Falling down	Count	8	4	4	3	19	
		% of Total	8.0%	4.0%	4.0%	3.0%	19.0%	
	Gun shoot	Count		4	7	3	14	
		% of Total		4.0%	7.0%	3.0%	14.0%	
	Explosive	Count			3		3	
		% of Total			3.0%		3.0%	
	Assault	Count		1	1	1	3	
		% of Total		1.0%	1.0%	1.0%	3.0%	
	Total		Count	22	44	22	12	100
			% of Total	22.0%	44.0%	22.0%	12.0%	100.0%

In this study, road traffic accident (RTA) was the first cause of **TBI** (61%). Falling down (FD) ranged from 3 to 8% (1-10 years = 8%, 11-20 years = 4%, 21-30 years =4%, > 30 years = 3%) and it is decreasing with time as individuals become more aware of road safety measures and concerned about their health and safety: negative relationship.

TBI due to gunshot (14%) and explosive (3%) injuries came in the third place after RTA and FD. The majority of individuals with **TBI** due to gunshot or explosive injury were 11-30 years old (11%). Four percent were children (11-20 years old), Ten percent of individuals with **TBI** due to gunshot or explosive injury were 21-30 years old which is young adult age. Assault (3%) and explosive injury (3%) were the least causes for **TBI**.

Table No. (12)
Caregiver relationship of TBI individuals
(N= 100)

Caregiver	Frequency(%)
Mother	63(%)
Father	16(%)
Wives	13 (%)
Brother	5 (%)
Sister	2 (%)
Others	1(%)
Total	100(%)

The majority of **TBI** individuals (63%) were receiving care form their mothers while fathers provided care to 16% of **TBI** individuals. **TBI** individuals receiving care from their wives were (13%), brother (5%), sister (2%) and father's spouse (1%). The majority of **TBI** caregivers were females (79%) while the minority were males (21%). Children with **TBI** in this study were found to be 60%.

Table No. (13)
Secondary Caregivers
(N= 100)

Secondary caregivers	Frequency (%)
yes	69 (69%)
No	31(31%)
Total	100 (%)

Sixty-nine percent, majority of **TBI** caregivers, were receiving help/support form other relatives while a minority (31%) where not receiving any help.

5.3 Scales used in the study:

5.3.1 Functional Independence Measurement (FIM):

Table No.(14)
Functional independence measure(FIM)
(N=100)

No.	Item	Scores (M/7)	Weight mean	Rank
Self-care				
1.	Eating	5.8	83.1	1
2.	Grooming	5.3	76.7	3
3.	Bathing	5.1	73.6	6
4.	Dressing-upper body	5.3	75.3	4
5.	Dressing-lower body	5.2	74.4	5
6.	Toileting	5.8	81.0	2
Subtotal		5.4	77.4	
Transfers				
7.	Bed, chair, wheelchair	5.9	84.4	3
8.	Toilet	5.9	84.7	1
9.	Tub, shower	5.9	84.6	2
Subtotal		5.9	84.6	
Locomotion				
10.	Walk/ wheelchair	5.9	83.7	1
11.	Stairs	5.5	79.0	2
Subtotal		5.7	81.4	
Communication				
12.	Comprehension	6.3	90.1	1
13.	Expression	5.8	83.7	2
Subtotal		6.0	86.9	
Social cognition				
14.	Social interaction	5.3	76.7	2
15.	Problem solving	5.4	77.0	1
16.	Memory	5.2	73.7	3
Subtotal		5.3	75.9	
Total FIM		5.6	80.7	

The highest performance of **TBI** individuals was seen in eating (weight mean = 83.1%) and Toileting (81.0%). The lowest performance was noticed in Bathing (73.6%) and dressing (74.9%). **TBI** individuals' performance in self-care ranged from 83.1 to 73.6% (needs supervision – modified independent). The average performance of **TBI** individuals (77.4%) was rated as "needs supervision". Individuals with **TBI** have good performance in transfer tasks (84.6%) they needed mild assistance or supervision to complete transfer tasks. Transfer tasks established mild burden and probably, needed

few time from caregivers. Walk/ wheelchair has weight mean 83.7% , and Stairs has weight mean 79.0%. For general the weight mean for the average score for all items related to locomotion are 81.4%.

TBI individual have highest performance in walking or wheelchair locomotion than ascending / descending stairs which is logical result. Comprehension has weight mean 90.1% and Expression has weight mean 83.7%. For general the weight mean for the average score for all items related to communication are 86.9%. Social interaction has weight mean 76.7% and Problem solving has weight mean 77.0%, and Memory has weight mean 73.7%, For general the weight mean for the average score for all items related to Social cognition are 75.9%. Generally for all items related to Functional independence measure, the weight mean are 80.7%. The highest score in FIM were recorded in communication (86.9%) while the lowest score were in self - care (77.4%). Therefore, self – care tasks were the most time consuming in activities daily living (ADL) tasks.

Table No.(15)
Bladder and bowel management
(N=100)

No.	Item	Continenence (%)	Incontinence (%)	Total
1	Urine	19	81%	100%
2	Stool	26%	74%	100%

In this study, most of **TBI** have urine incontinence (81%) while the rest have urine continence (19%). The patient who have stool incontinence were 74% while the individuals who have stool continence were 26%. The majority of individuals have urine and stool incontinence which adds more burden on carers in term of help and time needed to care such patients.

5.3.2 Disability Rating Scale (DRS):

Table No.(16)
Disability Rating Scale
(N=100)

No.	Instructions	Frequency (%)
Eye Opening		
1.	Spontaneous	97 (97%)
2.	To speech	2(2%)
3.	To pain	1(1%)
4.	None	0(0%)
Communication Ability		
5.	Oriented	57(57%)
6.	Confused	24(24%)
7.	Inappropriate	6(6%)
8.	Incomprehensible	10(10%)
9.	None	3(3%)
Motor Response		
10.	Obeying	96(69%)
11.	Localizing	1(1%)
12.	Withdrawing	2(2%)
13.	Flexing	1(1%)
14.	Extending	0(0%)
15.	None	0(0%)
Feeding		
16.	Complete	68(68%)
17.	Partial	18 (18%)
18.	Minimal	4(4%)
19.	None	10(10%)
Toileting		
20.	Complete	72(72%)
21.	Partial	9(9%)
22.	Minimal	6(6%)
23.	None	13(13%)
Grooming		
24.	Complete	57(57%)
25.	Partial	28(28%)
26.	Minimal	3(3%)
27.	None	12(12%)
Level of Functioning		
28.	Completely independent	4 (4%)
29.	Independent in special environment	23 (23%)
30.	Mildly dependent	20 (20%)
31.	Moderately dependent	8 (8%)
32.	Markedly dependent	42 (42%)
33.	Totally dependent	3 (3%)
Employability		
34.	Not restricted	12(12%)
35.	Selected jobs	25(25%)
36.	Sheltered workshop	6(6%)
37.	(Non-competitive)	57(57%)
38.	Not employable	0(0%)
Total		100 (100%)

Table No.(16) show that 97% from the sample have spontaneous eyes opening, 2% from the sample have eye opening to speech, and one o **TBI** individuals (1%) from the sample has eye opining to pain. The majority of **TBI** individuals in the study sample were conscious while three individuals (3%) with **TBI** were formed to be unconscious/comatosed. Fifty seven percent of **TBI** individuals were able to communicate with proper orientation while 40 individuals (40%) were able to communicate with confusion (24%) or has incomprehensible speech (16%). Three **TBI** individuals (3%) where aphasic and unable to establish any communication. Most of **TBI** individuals were (96%) able to obey verbal command while 4 individuals (4%) have lower motor response (localization, withdrawal or flexion). This result is consistent with results obtained in the same table as 97% where conscious and three percent were subconscious or comatose. Table No.(16) show that 68% from the sample were completely dependant in self - feeding. 18% from the sample needed partial assistance, 4% from the sample needed minimal assistance and 10% from the sample were completely independent and needed no assistance.

Table No.(16) shows that 72% from the sample were completely dependant in toileting. 9 % from the sample needed partial assistance, 6 % from the sample needed minimal assistance and 13% from the sample were completely independent and needed no assistance. In the same table shows that 57% from the sample were completely dependant in grooming. 28 % from the sample needed partial assistance, 3 % from the sample needed minimal assistance and 12.0% from the sample were completely independent and needed no assistance. More than half of the **TBI** individuals (57.0 - 72.0%) were completely dependant in eating, toileting and grooming. 9 – 23% of **TBI** individuals needed partial assistance in pervious ADL activities. 3 – 6% of **TBI** individuals needed minimal assistance. 10 – 13 **TBI** individuals were completely independent. These results add more profile to the results obtained from the FIM(negative correlation–0.91 at p- value equal 0.05).

Most of **TBI** individuals (73%) dependant in different degrees; 20% mildly dependant, 8% moderately dependant, 42% markedly dependant and 3% totally dependant. Four **TBI** individuals (4%) in the study sample were completely independent while 23% were independent in special environment. **TBI** profile in this study shows that most of the individuals (73%) need assistance with different degrees to perform activities of daily living. Great majority of **TBI** individuals in the current

study (57%) were non- competitive in terms of employability. 25% from the **TBI** individuals were able to do select jobs. Appropriate to their residual abilities. Six **TBI** individuals (6%, minority) were able to work in Sheltered / protected workshop. Another minority of **TBI** individuals (12%) have no restriction to do any work.

Table No.(17)
Disability Rating Scale in categories
(N=100)

Category	Item	Mean	Weight mean	Rank
(1) Arousability, Awareness and Responsivity	Eye Opening	0.04	1.33	4
	Communication Ability	0.78	19.50	
	Motor Response	0.09	1.80	
(2) Cognitive Ability for Self Care Activities	Feeding	0.56	18.67	3
	Toileting	0.60	20.00	
	Grooming	0.70	23.33	
(3) Dependence on Others	Level of Functioning	1.66	33.20	2
(4) Psychosocial Adaptability	Employability	2.08	69.33	1

Table No.(17) show that psychosocial adaptability in terms of employability established the first item in DRS for participants **TBI** individuals. While dependence on other (level of functioning) came in the second place. Cognitive and awareness abilities were in the third and fourth place according to DRS.

5.3.3 Community Integration Questionnaire (CIQ):

Table No.(18)
Caregiver performance(I) according to CIQ
(N=100)

Item	Alone (%)	With some one (%)	Some one else (%)
Shopping	29 (29%)	63 (63%)	8 (8%)
Prepare Meals	23(23%)	66 (66%)	11(11%)
Housework	17 (17%)	71 (71%)	12 (12%)
Caring for Children	13 (13%)	61 (61%)	26 (26%)
Social Arrangements	8 (8%)	80 (80%)	12 (12%)
Personal Finances	10 (10%)	23 (23%)	67 (67%)
Average %	16.6%	60.7%	22.7%

Table No.(18) shows that 29% from the sample of caregivers did the shopping %alone, 63% did shopping with another person and 8% didn't take part in shopping activity. 23% from the sample of caregivers prepared meals alone, 66% prepared meals with someone else and 11% from the sample of caregivers didn't prepared meals. 17%

from the sample of caregivers did the everyday housework in their home alone, 71% from the sample of caregivers needed assistance and 12% from the sample of caregivers someone else did it. 13% from the sample of caregivers cared their children at home alone, 61% from the sample of caregivers cared their children with another person and 26% from the sample of caregivers didn't take part in caring of children. 8% from the sample of caregivers planned alone for social arrangements, 80% from the sample of caregivers needed assistance and 12% from the sample of caregivers didn't participate in the same activity. 10% from the sample of caregivers managed alone personal finances, 23% and from the sample of caregivers someone else assisted them and 67% from the sample someone else did the activity.

To sum up, 16.6 % of **TBI** caregivers were able alone to perform daily activities such as shopping and personal finances, 60.7 needed assistance from some one and 22.7 % completely relayed on some one else in the same activities. This results is consistent with results obtained in table 14; great majority of **TBI** individuals (73%) need assistance.

Table No. (19)
Caregiver performance(II) according to (CIQ)
(N=100)

Item	Never (%)	1- 4 times (%)	5 or more (%)
Shopping (times/month)	8 (8%)	76 (76%)	16 (16%)
Leisure activities (times/month)	51 (51%)	44 (44%)	5 (5%)
Visiting friends or relatives	81 (9%)	9 (9%)	10 (10%)
Volunteer activities	72 (72%)	20 (20%)	8 (8%)
Average %	53.0%	37.3%	9.7%

Table No.(19) shows that 8% from the sample of caregivers didn't take apart in shopping outside home, 76% from the sample of caregivers did shopping 1-4 times a month while 16% from the sample of caregivers did shopping 5 or more times monthly. 51% from the sample of caregivers never participated in leisure activities such as movies, sports and restaurants, 44% from the sample of caregivers participated 1-4 times monthly and minority from the sample of caregivers (5%) participated approximately 5 or more times monthly. A great majority from the sample of caregivers (81%) didn't visit their friends or relatives, 9% from the sample of caregivers visited their friends and relatives 1-4 times monthly and 10 % from the sample of participated in social activities approximately 5 or more times monthly. 72% from the

sample of caregivers never engaged in volunteer activities in the past month, 20% from the sample of caregivers engaged in volunteer activities 1-4 times in the past month and 8.0% from the sample of caregivers engaged in volunteer activities in the past month 5 or more times.

CIQ collected important information (questions no. 7 to 9 and 15) about times (numbers) of shopping, leisure activities, visits and volunteer activities.

Table No.(20)
Leisure activities with who?
(N=100)

Item	Frequency (%)
Mostly alone	5 (%)
Mostly with friends who have head injuries	57 (57%)
Mostly with family members	38 (38%)
Total	100 (100%)

About half of **TBI** caregivers in the study sample (57%) participated in leisure activities with friends who have head injuries, 5% from the sample of caregivers mostly alone did leisure activities and 38% from the sample of caregivers participated in leisure activities with family members. None (0%) of **TBI** caregivers take part in leisure activities with friends who didn't have head injury.

Table No.(21)
Having a best friend
(N=100)

Item	Frequency(%)
Yes	83 (83%)
No	17 (17%)
Total	100 (100%)

A great majority of **TBI** caregiver (83%) in the current study have a best friend. While the rest (17%) didn't having a best friend.

Table No.(22)
Travel outside of home
(N=100)

Item	Frequency (%)
Seldom/never (less than once per week)	93 (93%)
Almost every week	4 (4%)
Almost every day	3 (3%)
Total	100 (100%)

A vast majority (93%) from the sample of caregivers seldom/never traveled outside the home, 4% from the sample of caregivers traveled every week outside the home and 3% from the sample of caregivers traveled every day outside the home.

Table No.(23)
Caregivers work situation
(N=100)

Item	Frequency (%)
Full-time (more than 20 hours/week)	14 (14%)
Part-time (less than or equal to 20hrs/week)	16 (16%)
Not working, but actively looking for work.	20 (20%)
Not working, not looking for work	50 (50%)
Total	100 (100%)

Fifty percent from the **TBI** caregivers in the study sample were not working and not looking for work, 14% from the sample of caregivers had Full-time work, 16% from the sample of caregivers had Part-time work and 20% from the sample of caregivers reported that they were not working but actively looking for work.

Table No.(24)
Caregivers and school or training program situation
(N=100)

Item	Frequency (%)
Full-time	1 (1%)
Part-time	9 (9%)
Not attending school, or training program	90 (90%)
Total	100 (%)

Ninety percent (90%) from the sample of caregivers didn't attending school or training program, while a minority (1%) from the sample of caregivers have a full-time training program situation and 9% from the sample of caregivers have a part-time training program situation.

Table No.(25)
Average score of CIQ
(N=100)

No.	Description	Score (M)	Rank
Home Integration Subscale			
1.	Shopping	0.8	5
2.	Prepare Meals	1.1	3
3.	Housework	1.2	2
4.	Caring for Children	1.3	1
5.	Social Arrangements	1.0	4
Sub average score		5.6	
Social Integration Subscale			
6.	Personal Finances	0.5	6
7.	Shopping (times/month)	1.1	3
8.	Leisure activities (times/month)	0.6	5
9.	Visiting friends or relatives	1.0	4
10.	Leisure activities (with whom)	1.3	2
11.	Having a best friend	1.7	1
Sub average score		6.2	
Productivity Subscale			
12.	Travel outside of home	0.1	2
13,14,15	Productivity	3.4	1
Sub average score		3.5	
Total average score		15.3	

The average score for home integration activities was calculated at 5.6 (56%), social integration activities 6.2 (50.8%) and productivity 3.5 (50%). The total average of the study sample (TBI caregivers) was found to be 15.3 (52.8%).

5.4 Correlations Between Scales:

Table No.(26)
Correlation between type of TBI gender and Community Integration
Questionnaire
(N=100)

Variables	Eta Correlation test (Nominal by Interval)	CIQ Scoring			
		Home integration subscale	Social integration subscale	Productivity subscale	CIQ total score
Gender	Correlation Coefficient	0.232	0.159	0.276	0.348
	p- value	0.634	0.511	0.563	0.319
	N	100	100	100	100

The critical value of r at degrees of freedom "98" and significant level 0.05 equal 0.195

The researcher use the Eta test correlation since the type of one variable is nominal (gender) and the other variable are numerical (CIQ Scoring) and the result in

table No.(26) which illustrate that the p-value greater than 0.05 for each subscale and total scale of CIQ. So the researcher concludes that there is no a correlation between gender and community integration score at significant level 0.05.

Table No. (27)
Correlation between Age of TBI and Community Integration Questionnaire
(N=100)

Variables	CIQ Scoring				
	Analysis (Person Correlation)	Home integration subscale	Social integration subscale	Productivity subscale	CIQ total score
Age	Correlation Coefficient	0.008-	0.104-	0.010	0.061-
	p- value	0.934	0.304	0.919	0.547
	N	100	100	100	100

The critical value of r at degrees of freedom "98" and significant level 0.05 equal 0.195

A person correlation test was used and the result illustrated in table No.(27) which showed that the p-value greater than 0.05 for each subscale and total of Community Integration score, so the researcher conclude that there is no a correlation between age and community integration score at significant level 0.05.

Table No(28)
Correlation between FIM (Subtotal Cognitive) and CIQ(Social Integration)
(N=100)

Variables	Analysis	CIQ (Social Integration)
FIM (Subtotal Cognitive)	Correlation Coefficient	0.784
	p- value	0.000
	N	100

The critical value of r at degrees of freedom "98" and significant level 0.05 equal 0.195

The researcher use a person correlation test Between FIM (Subtotal Cognitive) and CIQ (Social Integration) at significant level 0.05 in table No.(28) which illustrated that the p-value equal 0.000 which is less than 0.05, so the researcher conclude that there is a strong positive correlation between FIM (Subtotal Cognitive) and CIQ (Social Integration) at significant level 0.05.

Table No.(29)
Correlation Between DRS (Total) And CIQ(Total)
(N=100)

Variables	Analysis (Person Correlation)	CIQ(total)
DRS (Total)	Correlation Coefficient	- 0.814
	p- value	0.000
	N	100

The critical value of r at degrees of freedom "98" and significant level 0.05 equal 0.195

A person correlation test was used and the result illustrated in table No.(29) which showed that the p-value equal 0.000 which is less than 0.05, so the researcher conclude that there is a strong negative correlation between DRS (Total) and CIQ(Total) at significant level 0.05.

Table No.(30)
Correlation Between FIM (Total) And CIQ(Total)
(N=100)

Variables	Analysis (Person Correlation)	CIQ(Total)
FIM (Total)	Correlation Coefficient	0.527
	p- value	0.000
	N	100

The critical value of r at degrees of freedom "98" and significant level 0.05 equal 0.195

The researcher use a person correlation test and the result illustrated in table No.(30) which showed that the p-value equal 0.000 which is less than 0.05, so the researcher conclude that there is a strong positive correlation Between FIM (Total) and CIQ (Total) at significant level 0.05.

Table No.(31)
Correlation Between CIQ (Total) And DRS (Level of disability)
(N=100)

Variables	Analysis	Disability level	CIQ(total)
Disability level	Pearson Correlation		-0.345
	Sig. (2-tailed)		0.000
	N		100
CIQ (Total)	Pearson Correlation	-0.345	
	Sig. (2-tailed)	0.000	
	N	100	

The critical value of r at degrees of freedom "98" and significant level 0.05 equal 0.195

A spearman correlation test since the type of disability level is ordinal and the other variable (CIQ) is numeric and the result illustrated in table No.(31) which illustrated that the p-value equal 0.000 which is less than 0.05, so the researcher conclude that there is a strong negative correlation Between DRS (Level of disability) And CIQ (Total) at significant level 0.05.

CHAPTER "6"

DISCUSSION

- 6.1 Introduction**
- 6.2 Discussion**
- 6.3 Study Limitations**
- 6.4 Clinical Value Of The Study**
- 6.5 Conclusions**
- 6.6 Recommendations**
- 6.7 Summary**

6.1 Introduction:

The researcher in this chapter, will discuss the study findings, draw conclusions and illustrate study limitations. In addition, she is going to present the clinical value of the study. The recommendations will focus on future research in this area, suggest improving filing system in study setting, planning for new services in rehabilitation of **TBI** and raising the awareness regarding prevention methods of falls and Road Traffic Accidents.

6.2 Discussion:

This study aimed to examine the burden of **TBI** caregivers in the Gaza Strip. The study results demonstrated that caregivers experienced enormous burden. **TBI** profile in this study shows that most of the individuals (73%) need assistance with different degrees to perform activities of daily living so the participants in the study reported high level of disability burden after providing care to **TBI** individuals and lower level of community integration in the society (52.8%) due to caring **TBI** individuals. These findings are consistent with previous studies which suggested that caregiver have burden after **TBI** (Smith and Schwirian (1998); Marsh et al; (2002)).

The majority of **TBI** caregivers (53.0%) never did activities in the community such as shopping, leisure activities, visiting friends or relatives and volunteer activities, 37.3% did these activities 1-4 times a month and 9.7% did activities 5 or more times monthly. These results are consistent with pervious results obtained by (Serna and Sousa; 2006) who stated that roles of **TBI** caregivers had suffered most interruption due to the trauma were: friend, amateur/entertainment, family member and worker. The researcher believes that the burden is more obvious when the caregiver does not participate in community activities and prefer to stay at home to care the **TBI** individuals.

Are caregivers obligated or willingly do what they do?. The researcher reads that primary caregivers are obligated to a degree to divorce community activities such as shopping, leisure activities, visiting friend and volunteer work. On the other hand, there could be some caregivers who provide care willingly to **TBI** individuals. Nevertheless, both types of caregivers are deprived, due to time and necessary effort to care for **TBI**,

from taking part in community activities. The researcher believes that participation in community activities is necessary for balanced health.

The majority of our **TBI** participants (60%) were children who were 1-18 years old. Therefore, one can predict that children are more vulnerable to risk of RTAs and **TBI**. The report issued by the Palestinian Ministry of health for the year 2005 mentioned that RTA was the first cause of death amongst Palestinians who are 1-20 years old (24.2% - 29.2%) while lowered to third cause in 20 years and above (14.3%). May be this is a high ratio (60%) that's due to Gaza strip situation (social, economic and a large number of family members) so, mothers are busy with duties at home.

These findings are consistent with Gofin and Avitzour (2007) who found that the majority of **TBI** individuals (60%) were 17 years old or below. The researcher reads that, this category of population (1-18 years) are very active and not enough aware about risks causing **TBI**. Families who have children must be enough aware about disability caused and specially **TBI** risk factors such as road traffic accident (RTA) and falling down.

Sixty-nine percent, majority of **TBI** caregivers, were receiving help/support from other family members while a minority (31%) were not receiving any help. This finding is consistent with Finset and colleagues (1995); most interaction and support came from family members. The researcher believes that because there is no relatives near to them, or the caregiver may not trust people to take care for their **TBI** individuals.

It is a matter of fact, that extended family and/or large numbers family is common in Palestinian community. This fact makes one predicts that there will be a secondary caregivers for each primary caregivers, which could have positive impact in terms of lowering disability burden. But, this is not consistent with the study findings as the researcher found that disability burden and secondary caregivers were similar to other communities (Serna and Sousa; 2006 , Finset and colleagues; 1995).

The second cause for **TBI** was found to be falling down (19%) which is inconsistent with the CDC (2006) findings in which falling down was the first cause and formed 28% among those with **TBI**. Children 11-20 years old established the majority (35% from the total sample N=100) among those with **TBI** individuals due to RTA. Early childhood (1-10 years old) came in the second place and they formed 14% from

the whole study sample. The researcher refers that the age category 11-20 years old is the most active, has excessive freedom to play in street, has little supervision from parents and older family members and careless regarding road safety and parents' instructions. On the other hand, the children 1-10 years old are less aware about road safety measures. Parents, in some cases, can be careless and unaware enough about road risks. Moreover, Sander et al; (2003) in their study found that a substantial proportion of **TBI** caregivers had emotional distress and/or unhealthy family functioning before injury that could be in-depth searched in future studies in the Palestinian community. It is a matter of fact that the Gaza Strip has poor infrastructure regarding roads built, ineffective traffic signs system such as unclear cross walk and limited safe playing areas for children. The researcher refers that to poor safety measures in buildings and parents insufficient supervision of their children.

Based on observation, most of the people who are taking part in resistance against Israeli occupation are young adults. Israeli occupation and ongoing political conflict played an important role where **TBI** due to gunshot (14%) and explosive (3%) injuries came in the third place after RTA and FD. The majority of individuals with **TBI** due to gunshot or explosive injury were 11-30 years old (11%). Four percent were children (11-20 years old) which is a evidence that the Israeli occupation targets the Palestinian children during this war against Palestinian people. Ten percent of individuals with **TBI** due to gunshot or explosive injury were 21-30 years old which is young adult age.

Seventy-seven percent (77%) of **TBI** individuals were male. Male children were more prone to risk of having **TBI** due to RTA or falling down. This could be due to the fact that male children are more exposed to life dangerous events such as RTA, falling dawn form building and ware.

Most of the **TBI** individuals were male children (45%) while female children were (15%). The researcher addresses this result to parents, WHO and every Ministry of health. Urgent actions are necessary to investigate and minimize this risk on male children.

This result is in agreement with CDC (2006) which reported that the incidence and prevalence of **TBI** is greater among male individuals. Males in different groups are more exposed to disability risks such as RTA and falling dawn. The second cause for

TBI was found to be falls (19%) which is inconsistent with the CDC (2006) findings in which falls were the first cause and formed 28% among those with **TBI**. The researcher refers that to poor safety measures in buildings and parents insufficient supervision of their children.

The result showed us that the majority of individuals with **TBI** admitted in El Wafa Rehabilitation Hospital and Specialized Surgery are from Gaza city due to the fact that El Wafa Hospital located in Gaza city (47 out of 100). However, there are cases of **TBI** in other areas, but they are less admitted in El Wafa Hospital. Admission and accessibility to El Wafa Hospital must be reviewed in order to allow adequate opportunity of admission from different areas and avoid services deprivation. The researcher refers that this is not sufficient to provide all **TBI** individuals rehabilitation services. EWMRSSH is not raising this need as the staff used adults' bed for some children as alternative in these difficult situations.

The majority of **TBI** individuals (63%) were receiving care from their mothers. Children with **TBI** in this study were found to be 60%. Moreover, Perlesz et al; (2000) found that the majority of primary carers are females. The researcher agrees with the findings of Perlesz et al; (2000) and explains that the first mother's role is to look after children; therefore, they stay close to their children as a primary caregiver. Father takes another positions from responsibility from caring as working and most of day outside of home.

The researcher reads the above result in another way that most of **TBI** caregivers are mothers (63%) and most of them (53%) were deprived from community activities. This is a strong indicator that Palestinian mothers are under escalating pressure of general burden; caring and bringing up children and taking after sick or disable children. Moreover, Palestinian mother in term of stressor and burden. All that created sort of change in mother duties and role. For example: 60.7% of caregivers needed assistance from some one else to perform daily activities such as house work, prepare meals and caring of children.

Most of **TBI** have urine incontinence (81%) ,the results are consistent with Leary and colleagues (2006); which showed that incontinence was common in individuals with **TBI**.

In the FIM, memory (73.7%) and social interaction (76.7%) tasks formed the highest burden in social cognition tasks; therefore, they were more time consuming than others cognitive tasks. While in DRS cognitive and awareness abilities were in the third

and fourth place distressors. There is a strong positive correlation between FIM [Subtotal Cognitive (75.9%)] and CIQ (Social Integration(50.8%)) at significant level 0.05. This result consistent with Smith and Schwirian (1998) findings who pointed out that functional ability and cognition both are negatively affected by reported caregivers burden.

Forty three (43%) have communication disorders which ranges from severe aphasia (inability to express self or comprehend verbal speech) to confused speech. This is inconsistent with Schalen and their colleagues; (1994) who found in their study that there are more than 20% of **TBI** individuals who had speech disorders. At the same time, the highest performance of **TBI** individuals according to FIM scale was noticed in communication (86.9%) task; therefore, communication difficulty didn't establish time consuming task for caregivers.

A great majority of **TBI** caregiver (83%) in the current study have a best friend. While the rest (17%) didn't having a best friend. The researcher explains that as a part of Palestinian culture.

The researcher use a person correlation test Between FIM (Total) and DRS (Total) and the result showed that the p-value equal 0.000 which is less than 0.05, so the researcher conclude that there is a strong negative correlation (Correlation Coefficient = - 0.907) Between FIM (Total) and DRS (Total) at significant level 0.05. The researcher interpreted that as; the FIM scale measure the abilities of individual with **TBI** in this study and the individual have 126 that' mean independent and don't need assistance but if the score lowered from 126, so the individual need assistance and that's mean have a disabilities. This can be interpreted as follows: the FIM scale measures abilities while the DRS measures disability. Therefore they are tow faces for one thing; a positive and negative aspects.

Half of the **TBI** caregivers (50%) were not working nor looking for work. Ninety percent (90%) from the sample of caregivers didn't attend school or training program. The researcher explains that by their responsibilities and being busy with **TBI** individuals as most of **them** were females (mothers) who were busy with their **TBI** children. This result is consistent with Johnstone and colleagues (2003) who stated that the number of people who were working decreased by 55% and the number of people without jobs increased by 42.5% post one year with **TBI**. On the other hand, thirteen percent of the sample of **TBI** caregivers are not employed, but they were looking for

job. The researcher believes that it is a priority for **TBI** caregivers to receive a training program that will enable them to take after **TBI** individual and work as well.

The average score for home integration activities was calculated at 5.6/10 (56%), social integration activities 6.2 /12 (50.8%) and productivity 3.5 /7 (50%). The total average of the study sample (**TBI** caregivers) was found to be 15.3/29 (52.8%). Relevant to the DRS categories, Psychosocial adaptability in terms of employability established the most important item in DRS for participants **TBI** individuals 2.1/29 (7.2%) while dependency on other (level of functioning = 1.7/29 (5.9%)) came in the second place. Cognitive and awareness abilities were in the third and fourth place according to DRS (5.5%, 3.4%). This result could be regarded as community integration indicator for the study sample.

6.3 Study limitations:

There are some limitations in this study regarding:

- The ascertainment of Cognitive disabilities may not be reflected adequately by functional testing in the group of children and may be more important predictors of future school performance.
- The fact that there was a higher response rate among the cases does not affect the findings of a lack of association with activity limitations and with stress symptoms, although some residual misclassification may exist.
- Lack of accurate documentation of prevalence of **TBI** in Gaza Strip or the **TBI** individuals who are admitted in El Wafa Medical rehabilitation hospital or Ministry Of Health.
- Stigmatization that makes the **TBI** caregivers to be reluctant to participate in the study.
- Research assistance training difficulties as they were not familiar with research tools.
- Research tools were unavailable in Arabic which needed translation and accreditation.
- Complex political situation an lack of safety especially in distal areas near to the borders.

- In addition, high study costs in relation to current in come of researcher.
- In effective archive system in El Wafa Medical rehabilitation and Specialized Surgery (EWMRSSH).
- Some individuals were living in out of reach areas.
- Changes in clients personals date such as telephone number and address.

6.4 The clinical value of the study:

The clinical value of the study to **TBI** caregivers is to provide something to those people, this is especially important, in order to reduce the carers' burden. The findings suggest that carers may benefit from efforts to mobilize their skills in coping strategies such as problem solving.

The current study investigated the main concerns and challenges facing caregivers of **TBI** individuals. **TBI** individuals express their problems and needs when the researcher visited them at homes that give them support and follow up and give them feeling that they are neither segregated nor neglected.

Health policy decision makers will recognize and are more likely to address the real needs, drawn from the study findings, of **TBI** individuals and their caregivers. Meeting real needs might require vertical and horizontal development of delivered services to **TBI** individuals and their caregivers. This can be translated to more training on **TBI** rehabilitation, new specialized rehabilitation centers and new health promotion projects.

Health professionals agree that the quality of care and the health of the care-recipient are of vital importance. So the current study gives addition value to alleviate disability burden and enhance caregivers' community integration.

The clinical value of the study is to enhance responsible Rehabilitation organizations, governmental, non-governmental and international, to improve provided health services and advocate these individuals' rights. This study address major rehabilitation needs in the area of ADL retraining and vocational rehabilitation.

This is the first study to be conducted in the Gaza Strip about disability burden in **TBI**. It may establish opportunity for further research in the area of **TBI**, disability burden and community integration. Results of new research could be compared to this

study. Moreover, other types of disability could be investigated and compared in terms of disability burden.

The study highlights the importance of strategies for burden stress management followed in Palestinian health facilities that should be reviewed and aligned according to needs which are highlighted by this study.

6.5 Conclusions:

As a consequence of caring for the head injured person, burden in caregivers may increase. Caregivers may have many friends prior to the injury, many of whom may visit the head injured person during the initial hospitalization and give them a support. But after that, there is no body. At 6-months postinjury, after the **TBI** individual discharge from El Wafa Medical rehabilitation and Specialized Surgery (EWMRSSH), approximately half of caregivers reported clinically significant symptoms of disability burden as follows; anxiety, depression, and poor social adjustment (lowered of CIQ scores). Despite this, over time the person with **TBI**s behavioural and cognitive problems begins to play a larger role in the level of distress experienced by the caregiver. **TBI** occurred in 60% of the children. In addition, Palestinian mothers establish the primary caregiver of **TBI** individuals in the Gaza Strip.

6.6 Recommendations:

- There is a need for further studies to investigate **TBI**s in childhood (early and teens ages) in terms of causes with special focus on RTA which was also recommended by Sander et al 2003.
- There is a need to conduct a study that will investigate prevocational /vocational programmes of **TBI** individuals. Researchers are encouraged to study employment, unemployment prevocational and vocational rehabilitation programs, Disable Employment Act (1999) implementation and possible barriers.
- The researcher recommends that additional intervention in the area of ADL training and prevocational / vocational rehabilitation.
- The researcher recommends that Ministry Of Health (MOH) and El Wafa Hospital allocate enough beds or increase hospitals capacity according to needs.
- The researcher recommend that there is a need to establish independent, comprehensive, education, psychosocial adjustment, treatment and rehabilitation

center in Palestine for **TBI** individuals in accordance with international and Palestinian culture.

- Supporting the **TBI** individuals and their families on psychological, economical and social levels to enable them to reach independent level.
- Encourage outreach programs (rehabilitation services) to reach them at home and give them services in their community.
- Supportive and preventing through raising religious awareness, since religion has a great role in eliminating anxiety, depression, frustration, strengthening the will and accepting the reality of the events and protection against future relapses.
- Liaison with psychiatric services and ongoing training in mental health issues are important for caregivers of **TBI** individuals.
- Further study may investigate topics such as depression among **TBI** caregivers. (psychological status) and economical burden.
- Recommendation for families of **TBI**; Because Traumatic Brain Injury (**TBI**) is incurable, steps must be taken to prevent injury from occurring.
- Advice for the prevention of **TBI** is often common sense:

Fall Prevention Methods:

- Use the rails on stairways,
- Provide adequate lighting, especially on stairs for children or people with poor vision or who have difficulty walking,
- Place bars on windows to prevent children from falling.

TBI Prevention Methods Include:

- Always wear a seat belt in a motor vehicle,
- Always wear a helmet when on a bicycle, motorcycle, scooter,
- Use an appropriate child safety seat or a booster.

Road traffic accidents prevention methods include:

- For other mechanisms, such as being injured as a pedestrian or falling from heights, prevention measures require more intensive efforts focusing on environmental modifications and enforcement of regulations.

6.7 Summary:

Caring of **TBI** individual definitely includes impact on **TBI** caregivers. This impact is known as disability burden and it affects many aspects of care providers such

as activities of daily living, leisure activities, shopping and employment as well. The study findings are very important for all the community members, partners in MOH and social services, third party payers and researchers. **TBI** caregivers, whether primary or secondary, need to understand the nature and influence of disability burden and follow specific procedures to prevent gradual dissolving and evaporation under the pressure of disability burden. They need to push against negative influences on their daily life and cope with depressing impact on their satisfaction. Decision makers in the MOH and social affairs also have a responsibility in this regard. Mental health programs must cover this issue taking in account that most of **TBI** individuals are children and most of **TBI** caregivers are mothers. At the same time, these study findings should enhance further future research in this area which is multidimensional. WHO could benefit from the results and plan for community health and outreach programs in Palestinian community.

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APPENDIXES

APPENDIX (A)

ملحــــــــــــــــق رقم (3)

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APPENDIX (B)

ملحق رقم (1)

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APPENDIX (C)

ملحـــــق رقم (1)

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		.5
	()	.6
		.7
		.8
		.9
		.10
		.11
	()	.12
	()	.13
	()	.14
	()	.15
		.16
		.17
		.18



(DRS)

	=0		
	=1		
	=2		
	=3		
	=0		
	=1		
	=2		
	=3		
	=4		
	=0		
	=1		
	=2		
	=3		
	=4		
	=5		



	=0		
	=1		
	=2		
	=3		
	=0		
	=1		
	=2		
	=3		
	=0		
	=1		
	=2		
	=3		
	=0		
	=1		
	=2		
	=3		
	=4		
	=5		
	/ =0		
	=1		
	=2		

	=3		

	0
	1
	2-3
	4-6
	7-11
	12-16
	17-21
	22-24
	25-29



(CIQ)

	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	.1
	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	.2
	<input type="checkbox"/> <input type="checkbox"/>	.3

	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	.4
لا يوجد أطفال تحت سن 18 في البيت	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	.5
	<input type="checkbox"/>	
	<input type="checkbox"/>	.6
	<input type="checkbox"/>	
	<input type="checkbox"/>	.7
	<input type="checkbox"/>	
4-1	<input type="checkbox"/>	
5	<input type="checkbox"/>	
	<input type="checkbox"/>	



	<input type="checkbox"/>	.8
4-1	<input type="checkbox"/>	
5	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	.9
4-1	<input type="checkbox"/>	
5	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	.10

	<input type="checkbox"/> . <input type="checkbox"/>
<p style="text-align: center;">60</p>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

4-1
5

.15



		:6 5 3 2 1	❖	
			=2	
			= 1	
			= 0	
18		:4	❖	
	.5 3 2 1			
		: 9 - 7	❖	
			:	
		5	=2	
		4-1	=1	
			=0	
		:10	❖	
			:	
			=2	
			=1	
			=0	
		:11	❖	
			:	
			=2	
			=0	
		:12	❖	
			:	
			=2	

=1

() =0



:15 - 13

()

	:15	:14	:13
0=	+	+	
1=	4- 1 +	+	
1=	5 +	+	
0 =	+	+	
2=	4- 1 +	+	
2=	5 +	+	
0=	+	+	60
2=	4- 1 +	+	60
3=	5 +	+	60
4=	+	+	60
5=	/ 4- 1 +	+	60
5=	5 +	+	60
5=	+	+	60
3=	+	+	
4=	+	+	
3=	+	+	
4=	+	+	

5=		+		+	
4=		+		+	
5=		+		+	



		.1
		.2
		.3
		.4
		.5
<input type="checkbox"/>		
		.6
	(/)	.7
	/)	.8
	(.9
	()	.10
		.11
<input type="checkbox"/>		
		.12

