Children of parents with acute central nervous system injuries in Romania: Assessment of mental health needs and evaluation of an innovative preventive family intervention

Dissertation

zur Erlangung der Würde des Doktors der Philosophie

der Universität Hamburg

vorgelegt von

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aus Bukarest

Hamburg 2006

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Tag des Abschlusses der mündlichen Prüfung: 15.11.2006

Acknowledgements

In this way I would like to thank the persons, who supported me with the production of my thesis substantially.

First of all thanks to all children and adolescents, who were ready to entrust their personal thoughts and feelings and contribute in this way to the research!

My special thanks apply to Dr. med. Georg Romer, who gave me the suggestions to this work and who supported me from the right beginning. Without his inspiring ideas, his expert support and his large commitment my work would not have come surely in this form!

I would like to thank Professor Dr. Paul Probst for his encouragement and helpful suggestions, and also for his confidence and supportive attitude.

The moreover I thank Mr. Professor Dr. med. Peter Riedesser for the possibility of attaining a doctorate in the Department of Psychiatry and Psychotherapy for Child and Adolescents of the University Medical Centre Hamburg-Eppendorf and for the excellent work conditions provided.

Likewise I would like to thank all members of the Romanian COSIP Team, in particular Professor Dr. med. Stefan Milea and Professor Dr. med. Constantin Oancea for their support and advice.

I wish to express sincere appreciation to Professor Lucian Rosca for his guidance throughout the last years.

And my most cordial thanks go to my dear wife Monica and my beloved child Matei, who always are there for me and encourage me in my plans!

Dan Florin Stănescu Hamburg, 2006

Table of contents

1. Introduction

A severely ill person has to cope with medical procedures, hospitalisation, declines in socio-economic status, weakening of bodily strength, changes in bodily appearance, increasing dependency upon others, shifts regarding his/her future perspectives, and, in cases of a terminal prognosis, the direct threat to his/her life (Romer, Barkmann, Schulte-Markwort et al., 2002). If this person is a parent, the consequences of these stressor factors affect the entire family, which may result in a lasting distortion of the children's social and emotional development. It has long been known that somatic illness in a parent is a risk factor for later psychiatric disorders in children (Rutter, 1966), and despite this, little attention has been paid to children's mental health when a parent is severely ill, even though it is obvious that they represent the most vulnerable group of a population, and at the same time its greatest potential.

Publications that describe intervention programs for children of somatically ill parents vary widely in terms of target groups, contexts of recruitment, professions and institutions involved methods of intervention and the level of evaluation. In other studies on parents with cancer, multiple sclerosis, heart disease or haemodialysis it appeared evident that children of seriously ill parents had higher scores in symptom scales than controls with a tendency towards internalizing symptomatology. Armistead, Klein & Forehand (1997), suggested parental depression, withdrawal, interparental conflict, and parental divorce as factors mediating children’s maladjustment by disrupting the parenting function. In another review, Worsham and colleagues (Worsham, Compas, & Sydney, 1997), concluded that parental illness generally caused moderate levels of distress in children. Adverse effects on child adaptation had been found to manifest themselves mainly as internalizing problems, namely anxiety or depression. They pointed out that evidence of distress can mainly be demonstrated by children's self-reports, rather than by parental assessments. Other authors (Compas, Worsham, Epping-Jordan et al., 1994; Compas, Worsham, Ey et al., 1996), found out that subjective perceptions of a parental illness predicted child internalizing problems or distress better than did objective severity of the parental disease, and also that adolescent girls whose mothers had cancer reported more symptoms of anxiety or depression than girls whose fathers were ill or boys with an ill parent of either gender (Grant & Compas, 1995). Christ, Siegel, Freund et al. (1993) found that younger children often lacked knowledge about their parent's illness. Older children tried to fill these gaps with own speculations.

In acute central nervous system injuries, the evolution of illness is different from other severe illnesses in parents as described in the literature, such as cancer, diabetes, multiple sclerosis, AIDS, haemophilia. However, children reactions being exposed to an ill parent suffering for acute central nervous system injury are insufficiently known, as stated before, studies being almost inexistent.

The special characteristics of this acute condition and its course can be described as follows:

- from the very beginning the child learns about the event, which is usually an accident, as he or she cannot be "protected" by any so called "conspiracy of silence";
- the evolution of the illness is usually regressive to amelioration, but in the case of severe forms it is slow, with the risk of complication and deterioration;
- the successive emotional reaction of the family goes through a large spectrum from exaggerated hopes to sheer disappointment;
- the degree of existential disorganization is significant, often with massive emotional participation of children due to the direct contact with the ill parent, the reactions of healthy parent etc.

The analysis of the literature allowed some observations: Almost all the articles are concerned with the issue of acute traumatic brain injury only on adult members of the family. None of them makes any reference to children, although, empirically, they are a risk group for mental health problems. In Romania no previous studies on the mental health outcome in children of parents with acute medium and severe central nervous system injury was identified, and not even any concepts about mental health prevention. In the international literature, only two studies (Marsh, Kersel, Havill et al., 1998, Curtiss, Klemz & Vanderploeg, 2000) discuss the situation existing immediately after the accident and in the acute period. All other studies focus especially on the long-term consequences (after one year evaluation) and refer to: high stress level and family stress (Hall, Karzmark, Stevens et al., 1994; Douglas & Spellacy, 1996; Lanham, Weissenburger, Schwab et al., 2000; Minnes, Graffi, Nolte et al., 2000; Perlesz, Kinsella & Crowe, 2000), effects on the parent who provides the strongest support for the family (Kreutzer, Gervasio & Camplair, 1994), the factors which can anticipate the way the family can deal with the situation, the influence of the cultural environment (Simpson, Mohr & Redman, 2000), the factors which influence the way of adapting to stress, to family needs for psychological and social support (Serio, Kreutzer & Witol, 1997). However, no effects on children are reported. Nearly no reference is made to aspects related to children's psychic disorders or preventive intervention.

It has to be mentioned that in Eastern European Countries like Romania there is not a constant preoccupation for preventing the social and psychological problems of the children, families and parents in severe somatic conditions, neither from the part of the medical system, nor from that of the community; there is neither a previous experience related to coordinated activities in the field of mental health prevention in children of ill parents.

This present study has been conducted in the context of the international research project COSIP – Children Of Somatically Ill Parent (QLG-4-CT-2001-02378, 5th Framework Program QoL) which was funded by the EU and coordinated by the Universitätsklinikum Hamburg-Eppendorf, Germany. This project involved research teams from the following universities:

- Austria -Universitätsklinikum für Neuropsychiatrie des Kindes - und Jugendalters;
- Denmark - Aarhus University Institute of Psychology;
- Finland - Turku University Hospital Child Psychiatry Clinic;
- Germany - Universitätsklinikum Hamburg-Eppendorf (coord.);
- Greece - Athens University Medical School Department of Child Psychiatry Thivon & Livathias;

- Switzerland – Kinder und Jugendpsychiatrische Universitätsklinik und Poliklinik;
- Romania - University of Medicine and Pharmacy "Carol Davila" Clinic of Child and Adolescent Psychiatry „Dr. Al. Obregia” Hospital;
- United Kingdom - The Royal Marsden Hospital Department of Psychological Medicine.

The team structures and compositions are shown in Appendix A.

The self-understanding of the project was a collaborative networking study, and there was a harmonization of several procedures and measures, however, each study centre followed an own research agenda. The measures integrated in questionnaire packages were partly mandatory in each centre, others were optional depending on the particular research interest of each centre. For the present study, only data of the Romanian COSIP project are used. As the only centre within the European project, the Romanian one examined families, in which a parent was affected by acute medium and severe central nervous system injury.

1.1 Children of somatically ill parent – acute central nervous system injury

1.1.1 Life threatening parental illnesses as psycho-traumatic factor for children

Of course that it is almost impossible to consider all severe somatic diseases which may occur in parents. But, by taking into consideration the general characteristics of any serious parental illness, one can easily understand why they are considered potentially traumatic life events. Although, as it was mentioned before, most of the studies were focused on cancer, multiple sclerosis or AIDS, acute central nervous system injury, by its impact and consequences both for injured person as well as for family members (relatives of individuals with head injuries tend to do worse than relatives with other, equally severe disabilities), represent a disease with significant psycho traumatic potential (Orsillo, McCaffrey & Fisher, 1991).

The aim of this section is to give a short overview of the way in which psychic trauma could be understood. Thus, in its direct sense one could understand psychic trauma as an injury of the mind (gr*. trauma* = injury, wound). As the human biological organism can be surpassed regarding its resistance capacity, similarly our mental system can by surpassed in its defence capacity or vulnerability against life stressors. The analogy between psychic and somatic injuries is expressed in some of our common sayings, like: “this hurt me bad” or metaphorical language: “you break my heart”. Those kinds of metaphors emphasize the fact that we tend to interpret psychic injuries according to bodily experiences, as Freud said – the body ego is also the nucleus of the psychic ego, the centre of all mental experience. Paul Popescu-Neveanu (1978), defined trauma as an event of extremely intensity in someone’s life, which surpasses his capacities of adaptability. A traumatic situation must be understood as an interaction between internal and external perspectives, between environmental traumatic conditions and subjective designations of significance, between feelings and behaviours. A traumatic situation confronts the organism with “unbearable” information or stimuli which surpass its capacity of processing.

In this sense the diagnosis of a severe illness with an unfavourable prognosis or with remaining physical infirmities or malformations represents a potential traumatic situation for the ill person and his or her family. The traumatic events are defined in DSM IV (1994) as events which are outside of our normal mental outlook and those representing for almost everybody a severe stress. A person, who was exposed to a traumatic event like, experienced, witnessed or was confronted with one or more events involving a real death or death threatening, severe injury or danger of loosing bodily integrity of self or others corresponds also to the diagnostic criteria of posttraumatic stress disorder (“*DSM IV*”, 1994). In the same respect, the stress severity scale for children and adults from DSM IV (1994) comprise as being medium and severe stress factors the chronic and invaliding illness of a parent, chronic or mortal illness of a parent or different hospitalisations. Therefore, instead of conclusion we must emphasize that, life-threatening illness, chronically or acute, as well as physical illness from which a durable infirmity or malformation can be expected, are to be understood as potentially traumatic life events.

Although many professionals recognize the potential psycho traumatic effect of parental illnesses for children (Rutter, 1966; Lezak, 1986; Lewandowski, 1992), some of the most precious information came from those working on a daily basis with those kinds of cases, being directly involved in care process (DeBoskey & Morin, n.d.; Buzzel, 1994; Johnson, 2000). Therefore, thanks to their clinical experience, one could have now a broad image about the changes imposed to families and their members by the parental illnesses. The following section aim to offer a rather brief description of what acute central nervous system injury really means and it's the consequences.

By focusing our attention to families and children with acute brain injured parents, as a first step one must understand the specificity of the disease and its peculiarities. According to the Brain Injury Association of Washington, traumatic brain injury is an insult to the brain, not of degenerative or congenital nature caused by an external physical force that may produce a diminished or altered state of consciousness that results in an impairment of cognitive abilities or physical functioning (Uomoto & Uomoto, n.d.). It can also result in the disturbance of behavioural or emotional functioning.

The spectrum of brain injury can be divided into three main categories:

1. *Mild Brain Injury* - also know as "concussion," is only a brief, if any, loss of consciousness and no major complications like haematoma. Often, people with mild brain injury do not even go to a hospital. However, a relatively subtle amount of reversible brain damage occurs, even after a mild concussion. This is often followed by "post-concussion syndrome" that can include fatigue, temporary headaches, dizziness and mild mental slowing. The most important element in the management of mild brain injury is recognizing that the symptoms are real and can be treated. Symptoms of mild brain injury almost always improve over 1-3 months.

Another important element is the proper management of the resulting fatigue, with a gradual return to normal activities and/or work.

2. *Moderate Brain Injury* - results in a loss of consciousness lasting minutes or a few hours followed by a few days or weeks of confusion and may be accompanied by brain contusions or haematomas. Persons sustaining a moderate brain injury will usually have cognitive and psychosocial impairments that can last for many months. However, with treatment these individuals are often able to make a nearly complete recovery.

3. *Severe Brain Injury* - almost always results in prolonged unconsciousness or coma lasting days, weeks or even longer. Persons in a coma appear to be asleep, but cannot be awakened and have no meaningful response to stimulation. Such persons often have brain contusions, haematomas or damage to the nerve fibres or axons, and some may have suffered from anoxia. Although persons who sustain a severe traumatic brain injury can make significant improvements in the first year following the injury and can continue to improve at a slower pace for many years, they will often be left with some permanent physical, behavioural and/or cognitive impairment. In the initial period following a brain injury, the most common classification tool is the Glasgow Coma Scale (Teasdale & Jennett, 1976). This tool is a reliable measure of the degree of nervous system or brain impairment. In general, the more severe the injury, the lower the performance score. The scale does not necessarily predict how someone will eventually function in the outside world and it does not predict the level of independence an individual can attain following a brain injury. Using a numerical system, the levels of three main responses are graded - eye opening, best verbal response, and best motor response - with scores ranging from 3 to 15 obtained. The scale is outlined in the table 1 (Teasdale & Jennett, 1976). In the present study only children having parents with moderate and severe traumatic brain injuries, corresponding to a Glasgow scale score from 3 to 12 (severe 3-7, medium 8-12), were included (see methods part for detailed inclusion criteria).

Table 1

Glasgow coma scale

Response	Score
Eye Opening	
Spontaneous	4
To Speech	3
To pain	2
None	1
Best Motor Response	
Obeys commands	6
Localized movements	5
Withdraws	4
Abnormal bending and flexing	3
Involuntary straightening and extending	2
None	1
Best Verbal Response	
Is oriented	5
Confused conversation	4
Inappropriate words	3
Incomprehensible sounds	2
None	1

Brain injury can occur to anyone at any time. The statistics are staggering. In the U.S.A., over 2 million people suffer brain injuries per year, with 500,000 to 750,000 injuries being severe enough to require hospitalisation. Seventy-five thousand to 100,000 injuries result in death. Between 70,000 and 90,000 survivors are left with long-term deficits or disabilities ("*A brain injury guide for families*", 2003).

Each injury is unique and its outcome is unpredictable. Many injuries result in devastating, long term effects on the surviving individuals and their families. Others may experience a near complete recovery. Traumatic brain injury is associated with a host of physical, cognitive, personality, emotional, interpersonal, social, and recreational consequences that can greatly impact both the head injured person and his or her family (Uomoto & Uomoto, n.d.). Because these consequences often last over a period of months and sometimes years, families have to adjust to the changes in the head injured person, which results in changes in the family.

1.2 Impact on family and children

Brain injury has a tremendous impact on the family system, and places a significant demand on the emotional resources of individual family members. There are a myriad of emotional reactions typically experienced by spouses, the survivor and the family as all attempt to adjust to the brain injury.

1.2.1 Consequences on family life

In response to the initial news that a loved one has sustained a life threatening injury, families may experience shock and disbelief. The initial reaction of shock and denial can also be mixed with anger. It is understandable that one would be angry at the unfairness of a husband suddenly becoming injured, possibly not surviving (Uomoto & Uomoto, n.d.). At the time of injury, loved ones are immediately immersed in a medical emergency and emotional crisis for which no one can ever be prepared (Barry, n.d.). Injured individuals are brought to an emergency room, usually by ambulance. The family arrives separately, often after life-saving measures have been initiated. The hospital itself may not be familiar: dozens of strangers are caring for the injured person. In the midst of this medical emergency, family members are also in crisis. Feelings of helplessness and lack of control can become overwhelming. At a time when family members are desperately seeking answers, often vague responses are given by the medical staff, leaving the family such with uncertainties ("*A brain injury guide for families*", 2003). This is a period of great confusion, anxiety and terror for those in the waiting room while information regarding the patient's status is scarce. When sufficiently stabilized, the patient is transferred to the intensive care unit, and a new set of medical team members begin to manage his or her care. Thus, the acute hospitalisation of the brain injured family member is an extremely stressful event for the family. The spouse may need to take time off from work to manage family affairs, maintain the home, and make financial arrangements, while at the same time attempting to manage their feelings and fears (Uomoto & Uomoto, n.d.). Most energy is focused upon emotionally surviving the crisis and families are often exhausted and emotionally depleted as a result. In those initial stages of a severe head injury, the only behaviour that the family members are concerned with is “living” – day by day their major concern is for the life of the loved one (Dorsing, n.d.).

Empirical evidence exists that suggests that relatives of individuals with head injuries tend to do worse than relatives with other, equally severe disabilities, and it has been well established that the head injury impacts the family as well the patient, and that the stress and burden upon relatives are significant (Orsillo, McCaffrey & Fisher, 1991). Physical and emotional exhaustion is common as the process of recovery is long and slow. Recovery may be measured in weeks, months and years and slows with the passage of time. The effects of brain injury often are long lasting and recovery may be incomplete. Although some people with severe brain injuries experience only mild long-term difficulties, other people may require care or special services for the rest of their lives (“*Understanding Brain Injury: A Guide for Employers*”, 2000).

The entire family system and not just the individual have been "injured". The family system refers to the relationships and roles that family members fulfill in their daily lives with each other (Uomoto & Uomoto, n.d.). In the family system, if one member is ailing or for some reason cannot fulfill their customary role, another family member typically takes over the role. For example, the father who is brain injured may have been the financial manager of the family prior to the injury. As a result of brain injury, he may not be able to perform the necessary mathematical calculations required for budgeting. Therefore, the mother may be placed in the role of financial manager.

Emotional changes as a result of the brain injury can also mean that family members may react differently to the head injured person. For example (DeBoskey & Morin, n.d.), brain injury can result in an increase in anger problems and irritability in the survivor. Family members who interact with the survivor may find themselves more carefully choosing their words, or avoiding certain topics of discussion for fear of touching off an anger episode. Over a prolonged period of time of “walking on eggshells”, family members may become weary and lose their patience with the survivor, which may in turn make the survivor more prone to anger outbursts. Thus, the atmosphere in the family becomes much different than it was before the injury. Adjustment to the brain injury is often extremely difficult for spouses because they experience unique problems. Mourning can be complicated for the spouse since they often continue to live within their husband’s or wife’s physical presence but have, in effect, lost the person they married if significant personality changes have occurred. Sometimes the personality change in the survivor is subtle and not readily apparent to other family members or friends. Even spouses say they cannot “put their finger on it” yet something about their mate has changed (Uomoto & Uomoto, n.d.). If significant personality changes have occurred spouse and families grieve the loss of the person they once knew. As Mary Romano, a social worker has termed it, families mourn the "personality death" rather than the bodily death of the survivor (Uomoto & Uomoto, n.d.). This is one of the most complicated and painful aspects of adjustment to head injury. Often spouses and families are left with the uncomfortable feeling that they are living with a familiar stranger.

Lezak’s (1986) study suggests that depression is also a problem and a challenge for many of the parents and also for children in families that are contending with acute brain injury. The author stated that, in fact, one in five parents with acute brain injury are clinically depressed, or both parents were mildly depressed. According to Lezak’s study, children with parents having acute brain injuries commonly experience feelings of depression, anxiety and loss of attention. But, interestingly, in their findings (Orsillo, McCaffrey & Fisher, 1991), depression was not correlated with severity of the patient's injury measured by length of post-traumatic amnesia and duration of stay in the hospital. Rather, depression was found to be correlated with the relative's perception of personally change and deficits in the survivors. Also, the severity of the patient's injury did not show a linear relationship to degree of burden in the relative (Orsillo, McCaffrey & Fisher, 1991), although cognitive, behavioural, and emotional deficits were strong predictors.

Families bring to the task of coping with brain injury the same strengths and weaknesses they had prior to the survivor's injury. Even the strongest family has to rely on a tremendous amount of courage, flexibility, stamina, and understanding to endure the ordeal of brain injury. It has been said that the family is as much a victim as the survivor (Uomoto & Uomoto, n.d.). That is because we are more familiar with dealing with broken bones – in time all will heal and it will life at usual, but we are not at all familiar, however, with the "broken brain", and there is little data to tell us how long the healing process will take and if it will ever work like it did before. Thus, families are often ill-equipped to understand and cope effectively with the head injured patient (DeBoskey & Morin, n.d.). There has been a realization that the family suffers as much or more than the injured party. "When something like this happens, the whole family has a brain injury" (DeBoskey & Morin, n.d., p.35) a member of a traumatized family said - he was, of course, referring to the extreme feeling of disorientation and confusion that results after the initial shock and medical crisis have passed. Moreover, subtle inter-relationships of family members may be thrown off without an awareness of how to get moving in a positive direction. Confusion, shock, helplessness, grief, guilt and anger are just some of the many feelings family members may experience ("*Changes in Cognition, Emotions and Behavior after a Brain Injury*", n.d.). Some of these feelings may be directed toward the individual with the brain injury. These feelings are common reactions. No person or family is ever prepared for the reality of a brain injury and its consequences and it is extremely important that the main caregiver of the person with a brain injury and family members take care of themselves. Established family roles may need to change, school, work, and leisure activities are invariably altered. Several investigators (Orsillo, McCaffrey & Fisher, 1991) have suggested that the abrupt change in the patient's personality and behaviour that often accompanies head injury has the strongest impact on that family and is much more stressful than the accompanying physical changes. At the same time, those changes in the family system conduct to changes in family roles as well (Uomoto & Uomoto, n.d.) It is well known and accepted that each person in a family has specific roles they fulfill. For instance, traditionally the mother may be the "emotional caretaker" of the family. When personal crisis occur to a family member, the mother will provide emotional nurturance and support to that member. Traditionally, the father may have the primary or sole "breadwinner" role, 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 (Uomoto & Uomoto, n.d.). But, 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 the main source of financial income to the family, the whole family may suffer for 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.

1.2.2 Family reactions stages

Many families undergo a series of reactions as their perception of the patient's condition changes over time (Lezak, 1986). This process has been conceptualised in terms of six different reaction patterns, or stages (see Table 2, Lezak, 1986).

Some may experience all these stages, but at much different rates or even in a different order. Moreover, these stages tend to overlap, and they can shift back and forth as the patient exhibits a long-forgotten skill, as family members feel more or less burdened or fatigued, or as depression turns into anger.

Table 2

Family reactions stages

Stage	Time since hospitalisation	Perception of patient	Expectation	Family reaction
I	0-1 to 3 months	A little difficult because of fatigue, inactivity, weakness, etc.	Full recovery by one year	Happy
II	1-3 months to 6-9 months	Not cooperating, not motivated, self-centered	Full recovery if he'll try harder	Bewildered, anxious
III	6-9 months to 9-24 months; can continue indefinitely	Irresponsible, self-centered, irritable, lazy	Independence if know how to help him	Discouraged, guilty, depressed, going crazy
IV	9 months or later; can continue indefinitely	A different, difficult, childlike person	Little or no change	Depressed, despairing, "trapped"
V	15 months or later; usually time-limited	A difficult childlike dependent	Little or no change	Mourning
VI	18 to 24 months or later	A difficult childlike dependent	Little or no change	Reorganization – emotionally if not physically disengaged

Stage one – when the patient first returns home, many family members are so pleased and so absorbed with helping that they may notice few differences. In this stage, many families could present a tendency to hold on to the fantasy that the patient would “wake-up” and return to their previous level of functioning (Orsillo, McCaffrey & Fisher, 1991). Furthermore, relatives would often deny the patient’s disabilities and subsequently hold unreasonable expectations regarding the patient’s goals. The over-expectations and other form of “magical thinking” can serve to augment the stress and disappointment that both the patient and the family face (Lezak, 1986).

Stage two – a second stage begins as the family’s optimisms and energy start to wear thin. Family members become increasingly sensitive to the patient’s disruptive behaviour over the first year (ibid).

Stage three – in trying to understand what is happening, close family members – and particularly the responsible caretaker – tend to blame themselves, adding guilt to their bewilderment, frustration, and chagrin. Moreover, the patient’s disruptive and inappropriate behaviours and maladaptive reactions are crystallizing into habitual response patterns. It is at this time that many relatives first entertain the possibility that these changes may be permanent and that their own lives have been cruelly and irrevocably altered (ibid).

In the *third stage*, when conflicts – internal conflicts, conflicts between family members, and conflicts with the patient – are most intense, family members need to dissociate from the emotionally invested attitudes and ties and the habitual expectations that characterized their premorbid relationships with the patient (ibid).

Stage four – most family members ultimately struggle through the devastating transition from the initial assumption that the patient has remained the same person to the realization that the patient’s personality has been permanently altered by the head injury. They advance to a fourth stage when they understand that they are not responsible for the family’s emotional distress, and that the patient is probably not going to improve very much. Yet the caretaker can begin to think realistically about the future, the well-being of other family members, and the patient’s welfare only after achieving such awareness (ibid).

Stage five – the fifth stage is the period of active mourning, during which the family relinquishes hope that the patient's premorbid personality will return (ibid).

Stage six – emotional detachment may free caretakers from debilitating anger, guilt, or concern about propriety, and allow the family to rebuild a meaningful life.

Family members may be able to tolerate a life of self-denial for a few days or weeks, but no one can endure a regimen of emotional and social deprivation indefinitely without becoming physically ill, emotionally disturbed, or both, and the reality is that psychological counselling will not protect family members from the pain that marks these stages (Oddy, Humphrey & Uttley, 1978). However, psychologists who understand how head injury disrupts families can help them work trough these stages more rapidly and with less distress than they might without help (Lezak, 1986).

1.2.3 Impact on children

Although many friends, relatives and teachers assumed that an injured parent's discharge from the hospital and return home meant that everything was getting "back to normal", sons and daughters found this to be far from true. A parent's return home brought mixed emotions of joy, sorrow, frustration, disappointment, relief and anger for sons and daughters. Many spouses shared the same feelings. Rather than a celebration of wellness, coming home confronted families with how much a parent has changed. The possibility that things might never again be the same started to become real (Lash, 1993). As it was already mentioned, changes in a parent's personality and behaviour were among the most difficult adjustments for sons and daughters and the direct contact with this new reality might be hard to bear. Behaviours or reactions were sometimes opposite what they had been in the past. Lezak (1986) suggested that young children often bear the brunt of family's distress when a member sustains a head injury. Children may inadvertently be neglected by parents who are spending their time with the patient and trying to keep the entire family together. The financial resources of the family may also end up being directed toward the survivor of head injury, taking away opportunities for the healthy siblings, such as vacations, special family activities, or even higher education (Lezak, 1986). During the convalescence period, the brain injured parent status can be delusive. Although looking healthy, he or she is not the same as before: easily getting tired, they may have a hard time paying attention to anything for more than a few seconds, often rapidly forget especially new information, short term memory being affected ("*Understanding Brain Injury: A Guide for Employers*", 2000). The capacity of making effort is obviously reduced. This deficiency becomes more visible during the contact with others and also during other activities. He bears with much more difficulty the noise, loud music, and the presence of many persons around them, long time parties. He also very fast lose the interest for a longer, boring or too complicated activity, he becomes absent minded, instable, he switches to something else. Therefore, the moment of going back to his former activity or job must be chosen carefully. He needs a transition period with low activity until he regains his old abilities ("*Understanding Brain Injury: A Guide for Employers*", 2000). In some cases the deficiency remains permanent and the situation will be more difficult for everybody. Troubles can be represented by paralysis or equilibrium problems that can hinder walking. In severe cases the sizing of objects, self care and other essential activities of everyday life become difficult. In such situations, the injured persons need permanent help from the others. This is very difficult to give for a long period and often very difficult to receive by the ill person who can become whimsical, unsatisfied with the care he receives, by the rate of attention and devotion of the others.

The contact of children with the ill person can be difficult. Only with difficulty they learn when to stop, how to protect the ill parent but much more frequently, they forget that this has become a very sensible person. Children can very painfully resent the rejections from his part. In addition, when one parent becomes brain injured, an older son or daughter may take over some of the parenting roles for younger siblings. This son or daughter may become parentified (Uomoto & Uomoto, n.d.). This child "grows up quickly" in an effort to manage those responsibilities that were once filled by the injured parent. To a certain extent, a child may cope well with added responsibilities if their emotional needs are being met at the same time. However this role can be overwhelming if they are not able to share in common childhood or adolescent experiences such as adequate playtime with other children, or sufficient freedom to interact with peers outside of school (e.g., attend dances, participate in sports). While these are not consequences that are desirable in any family setting, these patterns can develop over a period of time and often without the family knowing that this process is happening.

1.2.4 Factors associated with children adaptation

There is still a great deal to be learned about specific types of treatments, their appropriateness for certain disorders, and the factors that contribute to treatment success and failure. It is clear that to reduce levels of childhood mental illness, interventions need to begin earlier, or ideally, preventive interventions need to be provided prior to the development of significant symptomathology (Greenberg, Domitrovich & Bumbarger, 2001). Public health models have long based their interventions on reducing the risk factors for disease or disorder as well as promoting processes that buffer or protect against risk. During the past decades, a number of risk factors have been identified that place children at increased risk for psychopathology. Coie, Watt, West et al. (1993), grouped empirically derived, generic risk factors into the following seven individual and environmental domains:

1. *Constitutional handicaps*: perinatal complications, neurochemical imbalance, organic handicaps, and sensory disabilities;
2. *Skill development delays*: low intelligence, social incompetence, attention deficits, reading disabilities, and poor work skills and habits;
3. *Emotional difficulties*: apathy or emotional blunting, emotional immaturity, low self-esteem, and emotional dysregulation;

4. *Family circumstances*: low social class, mental illness in the family, large family size, child abuse, stressful life events, family disorganization, communication deviance, family conflict, and poor bonding to parents;
5. *Interpersonal problems*: peer rejection, alienation, and isolation;
6. *School problems*: scholastic demoralization and school failure;
7. *Ecological risks*: neighbourhood disorganization, extreme poverty, racial injustice, and unemployment.

There appears to be a non-linear relationship between risk factors and outcomes, although one or two risk factors may show little prediction to poor outcomes, there are rapidly increasing rates of disorders with additional risk factors (Coie et al., 1993).

Regarding protective factors, although less is known about them and their operation (Luthar & Zigler, 1992; Rutter, 1987), at least three broad domains of protective factors have been identified. The first domain includes characteristics of the individual such as cognitive skills, social-cognitive skills, temperamental characteristics, and social skills (Luthar & Zigler, 1992). The quality of the child’s interactions with the environment comprises the second domain. A third protective domain involves aspects of the mesosystem and exosystem, such as school-home relations, quality schools, and regulatory activities (Greenberg, Domitrovich & Bumbarger, 2001). Similar to risk factors, some protective factors may be more malleable and thus, more effective targets for prevention. Coie et al. (1993) suggested that protective factors may work in one or more of the following four ways: directly decrease dysfunction; interact with risk factors to buffer their effects; disrupt the mediational chain by which risk leads to disorder; or prevent the initial occurrence of risk factors. By specifying links between protective factors, positive outcomes, and reduced problem behaviours, prevention researchers may more successfully identify relevant targets for intervention (Coie et al., 1993; Dryfoos, 1990).

1.3 Child mental health prevention in an Eastern European country

1.3.1 Development of an innovative child oriented family mental health service for patients with central nervous system injuries and their relatives

The whole project and not only the services provided, is absolutely new for Romania, and for many other European partners. The innovative character of the project is also sustained by the fact that it approach a vulnerable group at risk for mental health problems, that has been neglected by health care systems, by the fact that combine empirical study and research with real support and preventive intervention, and by the fact that involves also the somatic medical staff, and try to integrate the scientific knowledge in child and adolescent psychiatry about specific family needs and children's reactions to parental illnesses can be integrated into preventive efforts within somatic health care.

1.3.1.1 Primary prevention

In G. W. Albee's and J. M. Joffe's opinion (1977), primary prevention is the most misunderstood, under-supported, and neglected aspect of mental health work. Observations made by M. T. Greenberg, C. Domitrovich & B. Bumbarger (2001) regarding the fact that children's mental health needs are not yet properly considered in most of the countries represent a reminder both of current research limitations and field practice. Even though primary prevention has been described as a "magical notion", a "woolly notion" and "an illusion" (Albee & Joffe, 1977), it represents specific actions directed to specific populations. Because of this conceptual ambiguity and difficulties, a definition and a framework for understanding this notion are absolutely necessary.

Primary prevention, referring to actions taken prior to the onset of a disease to intercept its causation or to modify its course; *secondary prevention*, meaning early detection and intervention; and *tertiary prevention*, indicating rehabilitative efforts to reduce the residual effects of illness. In this conceptualisation, primary prevention has two aspects: *health promotion* referring to measures concerned with improving the quality of life and *specific protection*, denoting explicit procedures for disease prevention. Some practitioners, especially those in preventive medicine, have expanded the three levels to five, as follows (Albee & Joffe, 1977):

1. health promotion
2. specific protection
3. early diagnosis and prompt treatment
4. disability limitation
5. rehabilitation

This multilevel definition of prevention (Albee & Joffe, 1977) provides both a broad and convenient framework for accommodating almost all the activities of health workers as well as a justification for collectively including diagnosis, treatment, and rehabilitative functions under the rubrics of prevention. But the terminology is confusing and misleading, however, and contributes to the continued neglect and misunderstanding of primary prevention. That is why, G. W. Albee and J. M. Joffe (1977) advocate that prevention must be used solely to refer to actions which aim either to anticipate a disorder or, foster optimal health. In short, only activities that deal with health promotion or health maintenance, or what in the mental health field has been called positive mental health, would bear the label of prevention. As a recognized need for a conceptual clarity the above mentioned authors have evolved the following definition of primary prevention: “Primary prevention encompasses activities directed toward specifically identified vulnerable high risk groups within the community who have not been labeled psychiatrically ill and for whom measures can be undertaken to avoid the onset of emotional disturbance and/or to enhance their level of positive mental health.. Programs for the promotion of mental health are primarily educational rather than clinical in conception and operation, their ultimate goal being to increase people's capacities for dealing with crises and for taking steps to improve their own lives" (Albee & Joffe, 1977, p.20).

Within this theoretical approach, the stated objective of primary prevention efforts is not the prevention of mental illness. Rather, the goals of primary prevention are twofold: first, to prevent psychopathology and symptoms, maladjustment, maladaptation, and misery regardless of whether an end point might be mental illness; and second, to promote mental health by increasing levels of "well-being" among various defined populations. The concept of health promotion connotes a socio-psycho-cultural-educational model distinct from a medical model, and the overriding question becomes one involving social competence, coping ability, and ego-strengthening measures rather than criteria of psychiatric symptomatology. Of course that one cannot promise the eradication of mental illness through early intervention, but there is promise and hope in its conceptual mists at least to reduce its frequency and intensity. Greenberg, Domitrovich & Bumbarger, (2001) explains the role of developmental theory in prevention science, presenting an ecological model as well as a transactional model (the specification of risk and protective factors) as frameworks for organizing and guiding both basic research and the development of preventive intervention. An integrated perspective makes clear that both risk and protective factors reside at all levels of the child's ecology. Cynthia Hudley (2001) emphasize one aspect that permeates all levels of the child's ecology - the importance of culture in people's understanding of behaviour and the efficacy of preventive interventions, showing that intervention modalities may and must be different as against cultural models. It is very clear that, in order to reduce the intensity and risk of mental health in children, interventions must begin as early as possible, or, ideally, preventive intervention must be provided before significant symptoms appear.

1.3.1.2 Features of the public health care context in Romania

Placed at the middle between London and Ural Mountains, Romania's history was extremely agitated. First of all, due to the fact that it was placed at the confluence of three big empires, Russian, Turkish and Austro-Hungarian, then it was directly affected by WW1 and WW2, and right after for almost 50 years it was under a severe communist regime, suffering the well known consequences which has generated isolation, economical delay and different administrative and legislation systems comparing to the advanced European country (Milea, 2003). Nowadays, Romania is in a transitional stage, with a lot of new phenomena who accompany the economical, social, institutional and legislative reorganization process. Romania is a country with around 22 millions inhabitants, and its main town is Bucharest having almost 3 millions inhabitants, including the surrounding area. It is a well known town with, well developed cultural, economical and medical institutions**.** This large network of medical institutions includes universitary and non-universitary institutions, in-patient units and out-patient services for all categories of somatic illnesses. In Bucharest, psychiatric assistance is assured by territorial services separate for children and for adults, daily hospitals and two bed units. From those, the most important is "Al. Obregia" Hospital, with auricular structure, with more than 1300 beds (65 for child and adolescent psychiatry). It was built in the first half of the 20th century, and it was projected from the beginning as an institution for brain illnesses. In present in its frame "Al. Obregia" Hospital include both universitary clinics of pediatric neurology, child and adolescence psychiatry, psychiatry sections, gerontopsychiatry, resocialization, drug abuses and "Memory center". In its enclosure both "Cerebral-vascular pathology institute" with neurology clinic, and "Dr. Bagdazar" Emergency Hospital with neurosurgery universitary clinic, pediatric neurosurgery, recovery, orthopedy and cardiology are located. Between all these institutions there are strong functional relations, built during many years. In Romania, child and adolescent psychiatry was first established as a distinct medical specialty under the name of Child neuropsychiatry in 1948, and after this year it began to develop under the former socialist political context (Milea, 2003). After many attempts it was separated from the pediatric neurology in 1996. There are five universitary clinics spread all over the country (Bucharest, Cluj, Iaşi, Tg. Mureş and Timişoara), having both in-patient units and out-patient services (Milea, 2004). Regarding the tradition of treating the neurological illnesses, the focus was on the drugs or surgical interventions. The department of rehabilitation in neurosurgery founded 30 years ago was centered on speech therapy and physical rehabilitation. The psychically rehabilitation of the deteriorated patients with its complex problems was completely neglected. Ten years ago, from the traditional model of infantile neuropsychiatry the specialties of child and adolescent psychiatry and child neurology evolved. The newly found autonomy facilitated the development of child psychiatry, the passage from a more biological view to one dominantly psychogenic. Consequently the interest in psychological interventions as counselling, individual and group therapy, as well as family therapy increased.

In order to fully understand the context of implementation, we must take into consideration also economical and general policy factors. In this respect, we have noticed that there is a chronic under funding of the medical sector, a lack of money for the medical assistance and medical research. The resources are directed by the new state owned insurance system with absolute priority for somatic medicine. The mental health disciplines and services are left, into a secondary position. The first priority in public funding is the maintaining in function of the medical system, even at a minimal level, with a scarce allocation for development, research, medical education, preventive programs. The small programs of prevention developed by the Ministry of Health itself with centralized funding are oriented in directions in which there was a deep regression and heavy immediate consequences, as tuberculosis, diabetes mellitus and fighting against drug use. Possible for the future, one can expect a shift into major orientation of the Romanian medicine with more attention paid toward, these today neglected, fields as preventive actions, mainly due to large pressures from international level as European Union and inner professional groups. A substantial development in the medical field depends also from the future economical development of the country and new created resources. A second obstacle in the development of innovative preventive services is the quality of the administrative system, still in change, in process of passage from a state centralized medical system to a more local based one. The new responsibilities are not yet fully understood. The development of a complex system with state owned institutions, with a larger base including the new social agencies for protection mixed with a diversified private sector, with NGO's and private practitioners has created a degree of confusion in role attribution. This is a process in progress with positive trends, but needs more improvements until a healthy competitive system in allocation of projects and funds will be established. At the same time, the dominantly organic orientation of the traditional medicine with lack of trust, interest in psychotherapy, mainly due to a long time underdevelopment of the field of psychology in Romania, for cultural and ideological reasons, is also present. These shortages are also consequences of the education policy during the Ceausescu years (Milea, 2004). For decades, psychology, psychopathology and related knowledge about counselling and other psychotherapeutic interventions were forbidden. The former students, actual practitioners placed in key positions in Romanian medicine may have a low level of knowledge about the psychological needs, special needs related to the different illnesses, including somatic or neurological. Their weak interest for the mental health topic is reflected in their lack of interest for cooperation, for working in common teams in interdisciplinary research, their refuse to be placed in possible subsidiary roles. The prejudices about psychiatry, mental health and related topics, inherited from old time (Milea, 2004), are fully shared by the community, the general population, and are projected on psychology, which seems to be a cloudy, confuse science, not yet useful, with many indiscrete questions. All those factors reduce the capacity of families and of their physicians to recognize risks of negative psychological consequences of a severe parental illness on children. Therefore, the conspiracy of silence is a common coping strategy. This makes the fact understandable that, in this study a lot of families kept the serious life event far from the child's school, and did not give permission to involve teachers in assessing the child mental status in the frame of present research. Like in other European countries, mental health care is provided by a network of out-patient and in-patient psychiatric units, but the shortages in paramedical staff has substantially reduced the capacity of the child psychiatrists to take action in this field. They were focused on the care of current psychiatric disorders. The preventive interventions were scarce, centered on neuropsychiatric developmental delay of the institutionalised children. There have been only a few accents on the family interventions, excepting the psychotherapeutic intervention, aiming to improve the psychogeneses parental attitudes. Little was done in supporting the families being in existential crises (at risk of abandon, divorce, parental abuse, and parental illnesses).

Everywhere in the world the implementation of a new preventive intervention service may have to go through passive resistance, even with reluctance by the majority: the community, beneficiary and the professionals. Romania does not make an exception to the above mentioned statement, and one first step in coping is the identification of those obstacles related to its socio-economic context and finding of solutions for a substantial reduction of their negative influences.

1.4 Unresolved issues in the research field

Since the sixties of the last century the mental health risks for family members themselves, including children, generated by living with a severe somatically ill parent were recognized. Emotions as depression, fear, guilt or helplessness are fundamental effects of illness on the loving relatives. The painful process of change is lived by “healthy” persons of family very often at the limits of psychopathology but with a low awareness. But, as it was mentioned before, children whose parents are suffering from severe somatic illnesses have only recent caught the attention of those involved in mental health research and preventive intervention. In addition, children reactions being exposed to acute parental illnesses are almost unknown, researches in the filed being as inexistent, almost all publications analysed being concerned with the impact of acute traumatic brain injury only on adult members of the family. Moreover, children psychological symptomatology in case of parental acute central nervous system injury is insufficiently known, no data regarding their type and/or frequencies being available.

Following Greenberg’s (2001) integrated perspective which considers the identification and specification of risk and protective factors as frameworks for organizing and guiding both research and preventive intervention, one can easily observe that some basic variables of influence have not been included in previous research of children of somatically ill parents, especially of children with acute CNS injured parents. Therefore, identification of the protective and risk factors constellation is still an issue need to be answered.

The importance of culture in people's understanding of behaviour and the efficacy of preventive interventions was already emphasized (Hudley, 2001). Therefore, one must be aware that in Eastern European Countries like Romania, a real preoccupation for preventing the social and psychological problems of the children, families and parents in severe somatic conditions is still to be developed. Here, especially due to the fact that for cultural and ideological reasons psychological services have been forbidden and for a long time underdeveloped, one important aspect which is still to be analysed is represented by children and parents attitude toward this kind of intervention.

It has been well established (Orsillo, McCaffrey & Fisher, 1991) that the head injury impacts the family as well the patient, and that the stress and burden upon relatives are significant, and that the family suffers as much or even more than the injured party (DeBoskey & Morin, n.d.). As potential clients of an active preventive counselling, children position is often ambiguous, healthy, vulnerable or ill, possible depending on crucial periods of the course of illness evolution (Powell, 2001). This is the reason why the intervention has to be centered on the emotional reactions of children, using empathic listening, emotional support and a strategy of identification and development of family resources. The therapeutic relationship and edification of a therapeutic process (Rogers, 1987; Nelson-Jones, 1991; Oancea, 2002) are prerequisites for success of an intervention with desirable long-term consequences. The delivery of information about ill person and his illness passes on a second place. But, the methods used in mental health preventive interventions for children of somatically ill parents and their families are still in discussion. From the perspective of psycho-social medicine the presence or absence of a definite intervention intended to counterbalancing the secondary consequences of illness to families and children in particular is considered important. It is claimed that, in the case of an acute life threatening illness, the stressful reality cannot be avoided, but its psycho-traumatic impact can be reduced by protective interpersonal experiences (Lewandowski, 1992). The sensible points of any helping intervention are: the model, ways of communication, content of messages, duration and timing. In a preventive context, the psychotherapeutic model, better known as “brief therapy” (Truax & Carkhuff, 1967; Strong, 1968; Wollberg, 1980; Gillieron, 1997) seems to be most effective and reasonable, because interventions, in order to be justifiable for individuals that are not yet mentally ill, have to be not only effective, but also efficient in terms of limited efforts and costs needed. In the same logics, simple, cheap psycho-educational means mostly consisting in delivery of standard written information, as brochures intended to families in need, are reasonable means that have to be compared in their effectiveness with “face-to face” interventions. Attempts to help the relatives of ill persons started, through the spontaneous dialogues and explanations aimed to parents of handicapped children (McConkey, 1985). Later, the help was completed by brochures with information promoting a psycho-educational approach typically known as “living with a chronically ill …”. Their objective was to increase the understanding, acceptance and competency in those who care to ill persons. Their efficacy is already recognized. Therefore, one important question still to be answered is about the efficiency of one or another intervention method, especially in the field on preventive intervention for children with acute central nervous system injured parents.

1.5 Objectives, research questions and hypotheses

As have been presented in the previous sections, parental acute central nervous system injuries represent a real risk for psychological problems in their children. In order to investigate this issue and to get a rich picture of specific implications regarding children psychological outcome and family needs, the aim of the following section is to set up and present the main objectives of present study as well as research questions and derived statistical hypotheses.

1.5.1 Objectives

This study is based both on a cross-sectional study as well as on a longitudinal pilot intervention study in a controlled experimental design. The aim was to evaluate and compare the data obtained from 58 families and having a parent with acute central nervous system injury. In this thesis, the aim was also to specify interaction modalities of specific mental health risks and protective factors, as well as to evaluate different prevention intervention techniques for families and children having an acute CNS injured parent, combining in this way both empirical and applicative objective.

Empirical

- Analysis of the data concerning types and frequencies of mental health problems in children of acute central nervous system injured parents;
- Identification of specific mental health risk and protective factors for children of acute CNS injured parents;
- Evaluation of children’s and parent’s attitudes toward preventive intervention;
- Evaluation of the effects of prevention intervention techniques for families and children having an acute CNS injured parent in a controlled design.

Applicative

- Implementation of a model preventive intervention for parents and children from families with an acute CNS injured parent;
- Elaboration of a brochure (with advices) for parents.

1.5.2 Research questions and hypothesis

The first major set of hypotheses (Q/Hy A), will circle around the following research question:

Q A: Which types and frequencies of mental health problems can be found in children of acute CNS injured parents?

The following hypotheses were set up:

Hy A1: In children of acute CNS injured parents, emotional and behavioural problems are expected to be found increased as compared to a reference population.

> Hy A11: In children of acute CNS injured parents, emotional and behavioural problems as reported by parental perspective are expected to be found increased as compared to to a reference population.
>
> Hy A12: In children of acute CNS injured parents, emotional and behavioural problems as reported by self-perspective are expected to be found increased as compared to to a reference population.

Hy A2: If some mental health problems in children can be identified, they are expected to be mainly within the internalizing spectrum (anxiety, depression, withdrawal etc.).

> Hy A21: If mental health problems in children can be identified, as reported by parents, they are expected to be mainly within the internalizing spectrum.
>
> Hy A22: If some mental health problems in children can be identified, as reported by adolescent children themselves, they are expected to be mainly within the internalizing spectrum.

The second set of research hypotheses circles around the following research questions:

Q B1: What are the specific mental health risk and protective factors for these children?

Q B2: Are children's problems rather related to the depression of the healthy parent or than to objective severity of the disease?

The following hypotheses are set up:

Hy B11: High family dysfunction in general correlates positive with psychological symptoms of adolescents.

> Hy B111: The dysfunction in clarity and acceptance of the distribution of roles within the family correlates positive with psychological symptoms of adolescents.
>
> Hy B112: The level of dysfunction in behaviour control within the family correlates positive with psychological symptoms of adolescents.
>
> Hy B113: The level of a dysfunction in affective responsiveness within the family correlates positive with psychological symptoms of adolescents.
>
> Hy B114: The level of dysfunction in affective involvement within the family correlates positive with psychological symptoms of adolescents.
>
> Hy B115: The level of dysfunction in communication within the family correlates positive with psychological symptoms of adolescents.
>
> Hy B116: The level of dysfunction in problem-solving within the family correlates positive with psychological symptoms of adolescents.

Hy B12: The healthy parent’s own, subjective appraisal of physical and mental health (measured by SF-8) correlates negative with psychological symptoms of adolescents.

Hy B121: The healthy parent’s own, subjective appraisal of physical health correlates negative with psychological symptoms of adolescents.

Hy B122: The healthy parent’s own, subjective appraisal of mental health correlates negative with psychological symptoms of adolescents.

Hy B21: The depression of the healthy parent correlates positive with psychological symptoms of adolescents.

Hy B22: The medical objective severity of the disease as measured by Karnofsky Index correlates positive with psychological symptoms of adolescents as measured by YSR.

The next set of research questions refers to a longitudinal pilot semi-standardized intervention (exploratory trial). In specific, the following research questions were investigated:

Q C1: Do children’s detectable stress reactions as measured by psychological symptoms change over time after the traumatic event?

Q C2: Is a child-centered family counselling intervention especially designed for families with a CNS-injured parent more effective in reducing stress symptoms in children than an information brochure that gives guidance to parents and families how to address children’s needs in this situation?

The following specific hypotheses were set up:

Hy C11: The level of somatic complaints is assumed to increase after the ill parent returns home.

Hy C21: “Face-to face” interventions through counselling sessions are more effective in reducing children’s stress symptoms than written advices and recommendations by a brochure.

2. Methods

2.1 Defining and operationalizing variables

In present study, the selected variables included in analyse were splitted in the following well known groups: independent, moderating and dependent variables. Figure 1 shows the integrative model of all variable used. Regarding the independent variables, those are ill parent severity of illness measured by Karnofski Index and sociodemografic variables such as age, gender, educational level, all coming from BADO (basic documentation) questionnaire. As moderating variables it was selected healthy parent depression measured by BDI general score, healthy parent's quality of health-related life, measured by SF-8 mental and physical health component scales, and family variables such an overall measure of the health/pathology in the family measured by FAD scale "General functioning", the family's ability to solve problems without letting them disturb the family functioning measured by "Problem Solving" scale of FAD, the exchange of information between family members measured by "Communication" scale of FAD, the establishment of behavioural patterns within the family, for the purpose of managing a set of family functioning, assessed by scale "Roles", the extent to which family members are able to experience appropriate affect over different stimuli, including both happy and stressful events measured by "Affective Responsiveness" FAD scale, the interest in and value of other family members' activities and interests measured by "Affective Involvement" scale of FAD and the methods used to maintain certain behaviour in the family members measured by "Behaviour control" FAD scale. The dependent variables consist of second order scales (internalizing problems, externalizing problems and total problems) from CBCL (parental perspective) and YSR (self-reporting perspective).

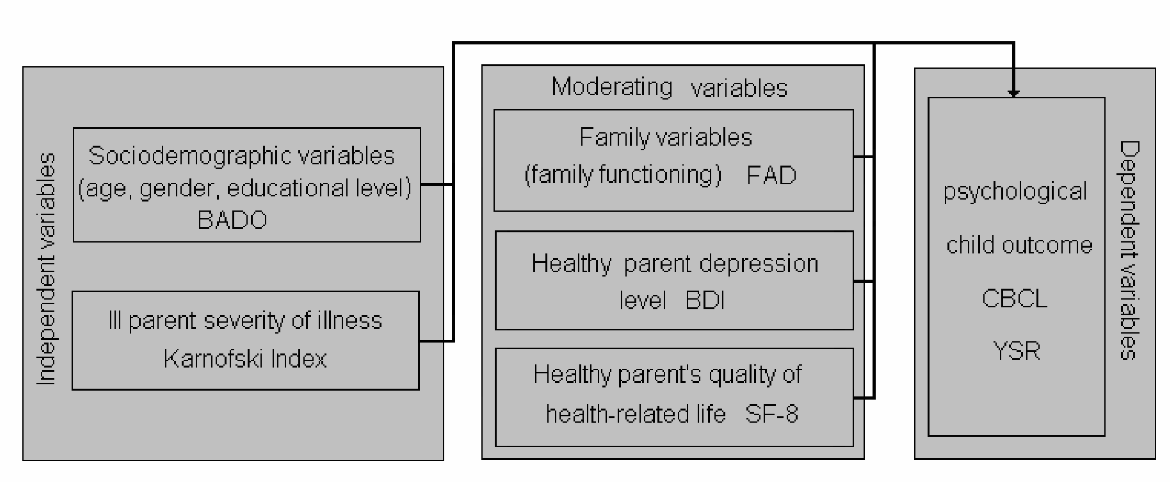

Figure 1. Reductional model of used variables

2.2 Methods and instruments

In order to reach the proposed objectives and to verify the above hypothesis, were used as methods, direct observation combined with interviews and questionnaires, both methods corroborated with the two intervention techniques - providing of psycho-educative information (via brochure) and psychological counselling. The following standardized instruments were administered to measure the operationalized variables as described above:

- **The Karnofsky Index** – for evaluation of a patient’s current physical state and performance, having the following values: 100% perfectly well; 90% Minor symptoms - can live a normal life; 80 % Normal activity with some effort, 70% Unable to carry on normal activity but able to care for oneself; 60% Requires occasional help with personal needs; 50% Disabled; 40% The patient needs nursing assistance and medical care, but is not hospitalised; 30% Severely disabled, in hospital; 20% Very sick, active support needed; 10% Moribund.
- **Basic Documentation (BADO)** it is mainly based on the Clinical Basic Documentation of the German Society of Child and Adolescent Psychiatry (DGUJPPP), which was modified and adapted for the COSIP Study Project to eight countries. It comprises documentation on sociodemographic and socio-

economical status as well as health and other information related to the family environment of the child. It contains the following modules: mothers on themselves, fathers on themselves, mothers on each child, mothers on their family, therapist on family and therapist on each child and module for the ill parent's physician. The full version is shown in the Appendix B.

- **Beck Depression Inventory (BDI),** for evaluation of the degree of parents' depression, version structured on 21 items having answers on a 4-point scale from 0 (not existing) to 3 (severe) with scores ranging from 0 to 63. Caseness was defined as scores in the moderate or above range (20 or above according to the BDI manual). The BDI has good psychometric properties with internal consistency of 0.93 reported in the manual (Beck & Steer, 1987).
- **Health Survey (SF-8)** version of the Medical Outcomes Health Survey (Ware, Kosinski, Dewey, & Gandek, 2001) measures physical and emotional quality of life. No clinical cut-offs are given. and convergent correlations ranging from 0.70 to 0.88 have been reported (Ware et al., 2001). The goal of developers of SF-8 was to reduce the initial number if items (SF-36) and to measure each of the 8 aspects of health with one single item. Thus they have created this generic multipurpose short-form survey of health status. In the 4-weeks recall version of the SF-8, which was used in this study, healthy parents were asked to rate several aspects of their health status during the preceding 4 weeks on a 5 to 6 point scale. The 8 aspects of health measured by the SF-8 comprise: General health, Physical functioning, Role physical, Bodily pain, Vitality, Social functioning, Mental health, Role emotional and two summary scales – Physical and Mental. Good psychometric properties have been reported with reliability coefficients of 0.70 or greater for each item (Ware et al, 2001) and test-retest reliability ranging from 0.61 to 0.70. (Ware et al., 2001).
- **Family Assessment Device (FAD)** by Epstein, Baldwin and Bishop (1983) is a questionnaire for evaluation of family functioning as a whole. The FAD, which is based on the widely known McMasters Model of Family Functioning (Epstein, Bishop & Levine, 1978), contains a total of 60 items. Higher scores on the FAD indicate a greater degree of family dysfunction. Besides a general functioning scale comprising 12 items, six sub dimensions of family functioning are

differentiated. The dimension “Problem Solving” (PS, 6 items) measures a family's capacity to resolve problems. “Communication” (CM, 9 items) assesses the degree to which verbal communication among family members is clear in content and direction, where ‘clear in direction’ means that the person spoken to is the person for whom the message is intended. The dimension “Roles” (RL, 11 items) measures repetitive patterns of behaviour by which individuals fulfil their parts in the management of family life. The degree to which tasks are clearly assigned to individuals is also considered. “Affective Responsiveness” (AR, 6 items) refers to family members' ability to respond with the appropriate emotion to each other. “Affective Involvement” (AI, 7 items) assesses the level of interest and value that family members have in each others’ activities. “Behaviour control” (BC, 9 items) encompasses the methods used in a family for expressing and maintaining rules. Differential profiles of family dysfunction based on these sub dimensions may inform goal-directed family interventions. The FAD items can be answered on a 4-point Likert scale from 1 = “strongly agree” to 4 = “strongly disagree”. Participants aged 11 years and older are asked to rate the extent to which they think general statements on how families may function match their own family. For each scale, answers for unhealthy coded items are reversed. Adequate test-retest reliabilities have also been reported (Epstein, Baldwin & Bishop, 1983). Discriminant validity of the FAD has been satisfactorily established by its ability to discriminate families with a psychiatric patient from those without (Epstein et al., 1983). The FAD can be completed by children and adolescents of 11 years and older. The reliability and validity of the FAD have repeatedly been proved to be good (Epstein et al., 1983). The reliability for each scale varies between .72 and .92 (Chronbach’s alpha), with general functioning having the strongest internal consistency (Epstein et al., 1983). The discriminative validity of the test is also strong as the results correlated well with clinicians’ ratings of healthy and unhealthy families (68-89%) (Epstein et al., 1983).

- **Child Behaviour Checklist (CBCL)** by Achenbach, (1991) parent/children version was used to measure emotional and behavioural problems in children and adolescents. In this questionnaire 113 items are listed in order to register emotional and behaviour problems. The parents are asked to assess, to which degree their child displayed the listed symptoms in the previous 6 months. The items are rated on a 3-point scale ranging from 0 = never, 1 = often, to 2 = very often. Besides describing children in terms of many specific items, the CBCL is also designed to identify syndromes of problems that lead on one factor. It displays the following first-order syndrome scales: Withdrawn, Somatic complains, Anxious/Depressed, Social problems, Thought problems, Attention problems, Delinquent behaviour, and Aggressive behaviour. Using factor analyses for these eight scales, the authors also were created the so-called second-order scales, with the syndrome scales designated as Withdrawn, Somatic complains and Anxious/Depressed grouped under the heading Internalizing Problems and the syndrome scales designated as Delinquent behaviour and Aggressive behaviour grouped under the heading Externalizing Problems (Achenbach, 1991). Moreover, a total problem score can be built by summing up all items. For all scales, higher scores stand for a greater degree of problems. In order to define the prevalence of clinically relevant problems (in the sense of a need for diagnostics, counselling or treatment) we used cut-off values described by Achenbach (1991). With a cut-off at the 83.rd percentile, the sensitivity and specificity of the total score adds up to 83.6% and 83.9%, respectively, among the German population.

- **Youth Self Report (YSR)**, a corresponding self-report version of the CBCL, was used for self-assessment of children (Achenbach, 1991). It is designed to be completed by 11 to 18 year-old children having a mental age of at least 10 years. Besides enabling youths to describe themselves in terms of many specific items, the YSR is designed to identify syndromes of problems that tend to occur together. The YSR includes 112 items referring to symptomatic behaviours and feelings that individuals rate on a 3-point scale as “not true,” “somewhat or sometimes true,” or “very true or often true” of themselves. By adding the respective symptom items, eight syndrome scales can be determined (withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent behaviour, and aggressive behaviour). By adding the respective syndrome scales, two spectrum scales and a total score can be obtained (internalizing, externalizing, total problems). In order to define the prevalence of psychological problems, I’ve used the so-called borderline cut-off values (T-scores

> 60) so that individuals with symptoms in the borderline range were included as defined cases. (Achenbach, 1991).

- **Opinion on the Counselling Procedure – FBB** (Fragebögen zur Beurteilung der Behandlung, Mattejat & Remschmidt, 1993) for evaluation of the therapeutically intervention quality: acceptability of intervention (0=completely ineffective, 1=predominantly ineffective, 2=partly successfully, 3=predominantly successfully and 4=completely successfully), success of intervention (0=no acceptability, 1=little acceptability, 2=moderate acceptability, 3=good acceptability and 4=very good acceptability) and total score scales - parent version QOCS-P 20 items, children version QOCS-C 20 items and therapist version QOCS-T 24 items.

The FBB is the most widely used instrument for evaluating interventions in child and adolescent psychiatry in the German speaking area. It has been slightly modified for this study by adapting some of the items to the context of preventive counselling (i.e. replacing “therapy” with “counselling sessions”).

2.3 Procedures

2.3.1 Implementation plan

Any program of psychological prevention of psychiatric disorders for family members of somatically ill persons, supposes important institutional developments, the initiation of mutual understanding and cooperation between somatic specialists and mental health professionals. Having in mind the fundamental questions such as: which are the characteristics of an ideal program of preventive counselling to be promoted by health authorities focused on the reduction of the risqué of mental disorders for family members of a severely somatically ill parent?; to whom is addressed such program: whole population or selective group of families whose characteristics remain to be established from the data obtained in this study or from other future researches?; and who will apply the preventive intervention, the institutions and persons involved?; the specific goals of the implementation were:

- to implement a pilot innovative preventive psychological intervention service for protecting mental health of children and families with a parent hospitalised for medium and severe acute central nervous system injury in Bucharest;
- to elaborate for the first time in Romania a guide for preventive counselling intervention with procedure to be followed.

2.3.2 Sample recruitment

Individuals were all patients with acute CNS injury, hospitalised in the three University neurosurgery clinics in Bucharest. In this respect:

- the COSIP research team directly contacted the administrative management and professional structures of the three clinics; we requested and succeeded in obtaining their cooperation agreement in order to identify and contact the target cases;

- the COSIP research team designed informative materials related to our offer, our purpose and work methods, materials for the medical staff in the neurosurgery clinics and for the family members of the patients hospitalised for acute CNS injury;
- a member of our research team had to monitor every day the hospitalisation and identify the cases that had to be contacted.

At the end, during a 12-months period, all the cases hospitalised with specific pathology at neurosurgery clinic from “Dr. Bagdasar” Emergency Hospital were monitorized. From those, all cases were selected fulfilled the inclusion criteria. All selected cases were repeatedly contacted in order to present them our offer, its scope and benefit and, on the other hand, to convince to accept and to sign the consent form. Only after consent signature the selected cases was included in the study and distributed in one of the experimental groups (control group/counselling group) according to odd-even rule.

Due to the fact that the obstacles and difficulties encountered in sample recruitment were so important, and therefore could be treated as a research question, a more extensive description of problems and lessons learned are reported in the results part.

2.3.3 Inclusion and exclusion criteria

The following inclusion criteria were defined:

a) for the family:
  - stabile domicile in Bucharest;
  - having a children between 4 -17 years old;
  - legally constituted family, both parents alive (typical family constellation).

b) for the ill parent:
  - brain injury severity between 3 and 12 on Glasgow scale (severe 3-7, medium 8-12);
  - hospitalisation in a neurosurgery clinic; approximately one week before living the hospital, after vital risk stage is overtake and amelioration evolution begin;
  - without somatically or mentally illnesses prior to current affection.

c) for the spouse / healthy parent:
  - consent signature;
  - minimum 4 years of school education;
  - speaking, reading and writing Romanian language;
  - without somatically or mentally illnesses prior to current affection of spouse.

d) for children:

- somatically health and without any treatment for psychiatric disorders prior to current traumatic event;
- between 4 -17 years old;
- living with both parents;
- no IQ deficiency,

and, for self reporting children:

- minimum 4 years of school education;
- speaking, reading and writing Romanian language.

Exclusion criteria

a) for the family:

- single parent;
- divorced;
- concubinage.

b) for children:

- knowledge of IQ deficit

2.3.4 Sample description

The present research comprised 58 families and children having an acute CNS injured parent, hospitalised at "Dr. Bagdazar" Emergency Hospital neurosurgery clinic – Bucharest. Because some of the following analyses will be calculated separately for children (aged 4-10) and adolescents (aged 11-18), the sample description is reported for the two groups.

In the child sample (age 4-10), data on n = 15 subjects were obtained. 9 child subjects were female (60 %) and 6 children subjects were male (40 %). The mean age of children was M = 7.26 years (SD = 2.37). Table 3 gives an overview of children's' gender distribution broken down by ill parent gender.

Table 3

Children's' gender distribution by ill parent gender

Ill parent	Boys 4 -10	Girls 4 -10	Total
Mother	1	3	4
Father	5	6	11
Total	6	9	15

Moreover within these 15 families, data were obtained from 11 mothers (M = 37.27 years, SD = 6.85) and from 4 fathers (M = 34.50 years, SD = 0.57), in our case the ill parent being considered not to be a reliable source of data. An overview can be seen in table 4.

Table 4

Parent's ages by gender (child sample)

Gender	M	SD	Range
Mother's age (years) (n = 11)	37.27	6.85	29 - 48
Father's age (years) (n = 4)	34.50	0.57	34 - 35

Regarding the somatic doctors' rating of physical health, no significant difference could be found between ill mothers (Karnowsky-Index M = 47.50) and ill fathers (Karnofsky-Index M = 54.45) with t (13) = .75 (p = .465; ns). The socio-economic status was operationalized via the highest completed school level of either parent. An overview can be seen in table 5.

Table 5

Parents' highest level of completed school education (child sample)

Highest levels of school education completed	Healthy parent (n = 15)
Low (< 8 years school)	3 (20 %)
Middle (9 – 12 years school)	10 (66.66 %)
High (academic)	2 (13.33 %)

The adolescent sample (age 11-18) consisted of n = 43 adolescent subjects between ages 11 and 18 (M = 14.04 years, SD = 1.81). 27 adolescent subjects are female (63 %) and 16 adolescent subjects are male (37 %). Within the 43 families, data were obtained from 43 adolescents, 24 mothers (M = 43.25 years, SD = 4.82) and 19 fathers (M = 40.36 years, SD = 6.95) in our case the ill parent being considered not to be a reliable source of data. Table 6 gives an overview of adolescents' gender distribution broken down by ill parent gender and table 7 of parent's ages by gender.

Table 6

Adolescents' gender distribution by ill parent's gender

	Boys 11-18	Girls 11-18	Total
Mother ill	8	11	19
Father ill	8	16	24
Total	16	27	43

Table 7

Parent's ages by gender (adolescent sample)

Gender	M	SD	Range
Mother's age (years) (n = 24)	43.25	4.82	32 - 51
Father's age (years) (n = 19)	40.36	6.95	32 - 57

Regarding the somatic doctors' rating of physical health, no significant difference could be found between ill mothers (Karnowsky-Index M = 53.16) and ill fathers (Karnofsky-Index M = 58.29) with t (41) = 1 (p = .323; ns). The socio-economic status was operationalized via the highest completed school level for mothers and fathers. An overview can be seen in table 8.

Table 8

Parents' highest level of completed school education (adolescent sample)

Highest levels of school education completed	Healthy parent (n = 43)
Low (< 8 years school)	5 (11.62 %)
Middle (9 – 12 years school)	30 (69.76 %)
High (academic)	8 (18.60 %)

Because some of the analyses were calculated separately for the intervention and control group, the sample descriptions for these two groups are presented separately. Families were assigned to either intervention or control group according to odd-even rule (even-control group, odd-counselling group):

- subgroup I made of 29 families – control group, who have attended four sessions of preventive counselling during a 6-month period;
- subgroup II made also of 29 families – intervention group, who have received a brochure (see Appendix I) with advice intended to reduce the impact of the event.

Table 9 and table 10 reflect the distribution of subjects in our two experimental groups, being observed a relative similar distribution of main indicators.

Table 9

Ill parent and children distribution by gender (intervention group)

Ill parent	
Male	20
Female	9

Children	4 - 10	11 - 18	Total
Boys	3	8	11
Girls	6	12	18

For this counselling group, data were obtained from 20 families with ill fathers (M = 40.35 years, SD = 5.74) and 9 families with ill mothers (M = 37.0 years, SD = 4.84), 3 child-age boys (age 4-10; M = 7.33 years, SD = 3.05) and 6 child-age girls (age 4-10; M = 7.00 years, SD = 2.52), and from 8 adolescents boys (age 11-18; M = 13.87 years, SD = 2.10) and 12 adolescent girls (age 11-18; M = 13.81 years, SD = 1.78).

Table 10

Ill parent and children distribution by gender (control group)

Ill parent	
Male	15
Female	14

Children	4 - 10	11 - 18	Total
Boys	3	8	11
Girls	3	15	18

For the control group, data were obtained from 15 families with ill fathers (M = 42.73 years, SD = 6.54) and 14 families with ill mothers (M = 40.85 years, SD = 7.41), 3 child-age boys (age 4-10; M = 7.66 years, SD = 2.08) and 3 child-age girls (age 4-10; M = 7.33 years, SD = 3.05), and from 8 adolescents boys (age 11-18; M = 14.12 years, SD = 1.95) and 15 adolescent girls (age 11-18; M = 14.40 years, SD = 1.80).

2.3.5 Description of the counselling intervention

Intervention was developed by using the following stages: the emphatic listening of parents, the operationalization of the educational and relational problems with their children and effective "guidance" ended with the elaboration of a set of fruitful attitudes for the family. In conformity with main theoretical schools of psychotherapy, the therapeutic procedures of counselling were oriented in at least two different directions, the peculiarities of the cases imposing the selection of one or another:

a) first more analytical oriented. The objective of counselling is to increase the parents' insight and their tolerance toward the child behaviour. A related objective is to develop the parents' awareness on the unconscious roots of their own attitudes toward the child, which can stimulate very often reciprocal adverse answers. It is a model of emotional supportive intervention targeted to cognitive-affective restructuring of the parents, the understanding being central one, with the hope of consequent improvement of family climate.

b) second more behavioural oriented is related to role of the conditioning process and of learning into the quality of parent-child relationship and in process of social adjustment. The practical part of counselling is far more directive, consisting in elaboration in cooperation with the parents, of precise programs and strategies aimed to reduce the undesirable behaviours and to increase to desirable ones. That leads to the increase of parental educational skills.

Intervention, consisted in direct counselling sessions with children, placed at monthly intervals. Their number was conventionally established as equal for all cases (four). The objectives of early preventive counselling on the family were oriented toward:

- reduction of emotional stress on the family generated by psycho traumatic event of a severe life-threatening illness, prevention of the development of psychiatric disorders in children;
- introduction of a realistic communication style between parents and children about the psycho traumatic event and its possible bad consequences;
- affective and cognitive reorganization of parents and children;
- development of resources and creating of coping strategies adjusted to new situations: getting the competence for care of ill person, better use of time, maintaining an acceptable level of social and professional life;
- assessment of the quality of psychotherapeutic intervention.

For more details regarding counselling concept and its setting see Appendix C.

2.3.6 Data collection and data management

For the beginning, both samples were evaluated at the moment of inclusion t_0, using commonly agreed questionnaire packages. After that, the intervention group was intermediary evaluated at t_1, one month after the moment of inclusion - because we supposed that for children, psycho trauma has two moments: the one of confrontation with the news of parent illness and hospitalisation, and the second, the impact generated by the return of ill parent into family and the new every-day family reality. At the end of the study, 6 months after the moment of inclusion t_2, both intervention and control group were again evaluated. Supplementary, the intervention group received four face-to-face counselling sessions – at the moment of inclusion, one month later, in the 3rd month and in the 6th month. At the end, after 6 months, the quality of counselling was evaluated using the evaluation questionnaires for children/parent and therapist. The control group received a brochure, which was elaborated especially for this purpose. The brochure used followed a somewhat similar design as that of counselling intervention including a preliminary part dedicated of the understanding of own reactions toward illness, of healthy conjoint and the children and substantial

advices for coping with them. This decision to use this brochure was also driven by ethical reasons in order to offer some support to all families approached.
The data obtained at the beginning of the intervention (t0 – initial evaluation) were evaluated and compared with those from the first month (t1 – intermediary evaluation), and with those from the sixth month (t2 – final evaluation). At the same time, in a pilot semi-standardized intervention (exploratory trial) we have compared the data obtained from (in a pre-post measurement design) families getting counselling with those from the second group of families, who solely are given a brochure and serve as controls. For each of those families the respondents were the healthy parents (because the ill parents were not a reliable source of information), and the child with the birth date closest to that of the ill parent (in case of siblings).

All procedures of data collection were well documented and all materials used in data collection were collected and archived. The scientific standards of data collection are documented in Appendix D. One of the most important aspects of any research it is represented by data management issues. In this respect, the coordinating center of the COSIP study project (University Medical Centre Hamburg - Eppendorf) created clear organized data management procedures, (Appendix E), in order to assure the requested quality of both quantitative and qualitative data. These standards of quality assurance in data management, including missing data issues are documented in Appendix F and G.

2.3.7 Data analysis

The data were analysed in three stages. First, in a cross-sectional analysis of the data collected at t_0, descriptive statistics were generated for the demographic variables and for each of the measures provided by each of the informants (mother, partner and child) as applicable. For the CBCL and YSR, raw Internalizing, Externalizing and Total Problems scores were generated and then transformed, to standardized T scores. To identify child problems, the CBCL and

YSR data were dichotomised into ‘cases’ vs. ‘non-cases’, using standard cut-off scores. Considering the fact that there are no norms for CBCL and YSR in Romania are available, a decision was made to use German norms instead of American ones due to greater social and cultural differences between Romania and United States. A problem case was defined by a score provided by an informant (mother, father or child) that exceeded the clinical or borderline-clinical CBCL or YSR cut-off score for such informants. The corresponding hypotheses were investigated using comparison of differences between norms and reported results (both by parental perspective – CBCL and by self-perspective - YSR). For this T tests were used, also because T tests are recommended to be used when in any of the comparison groups are less than 30 subjects (Sava, 2004).

In Stage 2, an explorative analysis was performed to determine which variables were predictors of YSR casesness. For examining the predictive power of the selected variables, such as illness severity, parents’ objective physical impairment, parents’ subjective well being, parental depression, family relational functioning or for children’s psychological outcome, in a first step, Pearson correlations were calculated between any of the respective scores and the second order symptom scales of YSR due to the fact that it was interested to find children opinion, although some one could encounter possible social desirability biases. In a second step, the results of the previous correlations were used to identify the set of variables, which could best predict psychological problems of children and adolescents through means of multiple regression analyses. In stage 3, a comprehensive analysis was undertaken both for parental perspective (CBCL) and for self-report perspective (YSR) in order to test our previous stated hypothesis. Therefore, the data obtained at the beginning of the intervention (t0 – initial evaluation) were compared with those from the first month (t1 – intermediary evaluation), and with those from the sixth month (t2 – final evaluation). At the same time, in a pre-post measurement design, the data obtained from families getting counselling were compared with those from a control group of families, who solely were given a brochure. Scientific standards of data analysis are documented in Appendix H.

3. Results

3.1 Problems encountered in sample recruitment

Unfortunately, the lack of psychological services from two of the university clinics we choose, did not allow us to include a psychologist who constantly worked in their team in the respective clinic. Once we started to identify the eligible cases, we also faced the first problems. That consisted mostly in the passivity, lack of interest and even passive resistance of the medical staff in the neurosurgery clinics. On the daily visit of the COSIP contact person, the specialists gave several reasons to justify their lack of support to our attempt to contact the patients' families: the lack of suitable cases for the selection criteria (although it was obvious that only the team members could select the cases), lack of time, the seriousness of the patient's disease, the fact that they had other priorities as well as other arguments which made us realize that they considered our objectives insignificant (or to common as compared to the other problems of the cases). As a result, our attempt to re-establish a subsequent dialogue with the neurosurgery specialists in order to improve our collaboration leads to a final refusal by two of the clinics' management to collaborate further on. Their major argument was the forensic nature of cases (most of them were car accidents or aggressions), a situation in which any involvement of persons outside the institution could be charged to them later by the litigating parts. Only one neurosurgery clinic that had its own psychology cabinet was left available. This mediated the access to the patients' families and contributed a lot to our supplementary efforts in the first months to convince them that we were not interested in interfering with medical procedures, but were interested in getting in contact with patients' families and their children.

In Romania the use of communication with families through modern means (phone, fax, E-mail) is somehow limited and so our team members were obliged to get home visit in the majority of cases. This is a time-consuming procedure but has the qualitative advantages of direct contacts and getting data that are more reliable. A large variety of reasons for refusal, were schematically grouped in the following categories:

- overwhelming and exceeding present burden;
- lack of trust and even incapacity of understanding the role of preventive psychological prevention;
- main need is represented by lack of material support;
- the wish to minimize the situation and its consequences and not to complicate it with new problems;
- fear of making decisions without partner consent;
- refusal of children involvement and of outside interference in personal problems.

From 2124 cases hospitalised with acute central nervous system injury 1312 were identified with medium and severe specific pathology. Out of them, 1076 (82%) cases did not fulfill our inclusion criteria. 254 (19%) cases matched the selection criteria. Out of these, 85 cases were lost by decease and 24 by other reasons. 145 cases were requested to sign the consent. Out of those, 87 (60%) cases refused to collaborate, 58 (39.8%) cases signed the consent form, 36 of them (62%) after repeated contacts. A second group of cases was made only from refusals (87 families) and it was evaluated the reasons for refusing our offer for a mental health intervention. During a 6 months period, two drop-outs were recorded, one in each of the experimental group (intervention and control).

3.2 Question block A

Prior to analyses, CBCL and YSR internalizing, externalizing and total symptom raw scores were transformed into normalized T-scores (Achenbach, 1991). As we have stated before, in Romania there are no norms yet for those instruments, and we have decided to use German norms as reference. We planned to answer our hypotheses in block A by comparing the previous calculated means for externalizing and internalizing behaviours as well as for somatic complaints of children and adolescents having a parent with acute central nervous system injury, both from parental perspective and self-perspective with the German norms as reference. At the same time data will be analysed using within group comparison regarding prevalence of internalizing or externalizing behaviours, again using both perspective (parental perspective - CBCL and self-reporting – YSR). For the following analyses, one has to keep in mind, that the power of the current sample is limited.

3.2.1 Parental reporting perspective

At first data on children's and adolescent's internalizing, externalizing and total problems were looked at using parental perspective, aiming to answer at Hy A1 and Hy A2 and to the corresponding sub-hypotheses Hy A11 and Hy A21.

Regarding Hy A1 and sub-hypothesis Hy A11, in parental perspective, 11 out of 23 girls (47.82%) and 7 out of 16 boys (43.75%) scored above the borderline cut-off for total problems in the CBCL, as compared with expectedly 16% in the reference population, and thus almost three times as high than in a reference population. Figure 2 shows the symptom's prevalence in the second order scales for CBCL for boys and figure 3 for girls. In 9 out of 16 cases of boys aged 11 – 18, and 13 out of 27 cases girls aged 11 – 18, data were only obtained from the self-reporting perspectives. This resulted in according missing in the parental reporting perspectives.

The percentages of subjects scoring above the borderline cut-off for internalization problems was 52.17% for girls and 35.71% for boys, exceeding for more than three times (for girls) and more than two times (for boys) the reference population (16%). The percentages are little lower for externalization problems with 43.47% for girls and 21.42% for boys, but these are also almost three times higher (for girls) than in a reference population. A comparison between the two gender groups revealed a higher rate of symptomatic individuals among girls. Taking into consideration all the above mentioned results, the Hy A11 is confirmed for both analysed groups (boys and girls), with an increased level of symptomatology in girls as compared to boys.

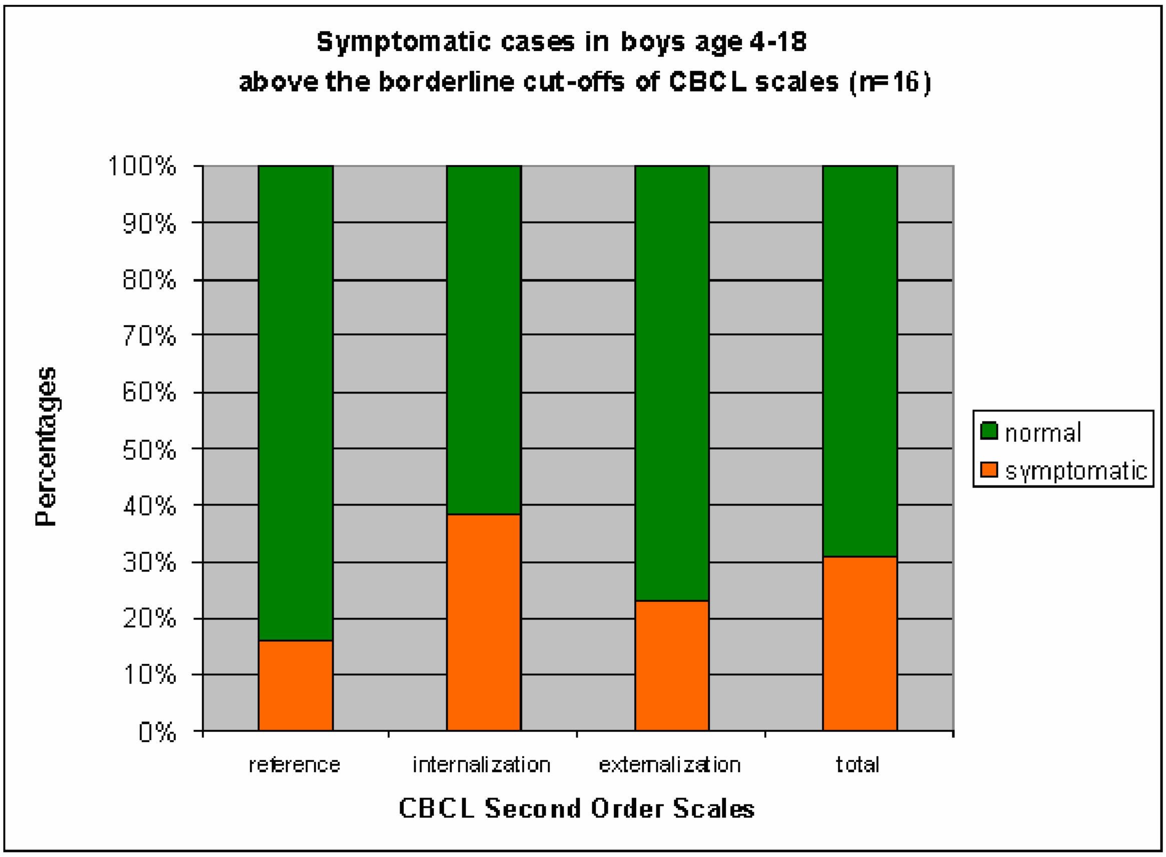

Figure 2. Prevalence of symptomatic children and adolescents (boys) in parents' reporting perspective (CBCL).

Regarding the hypothesis that if some mental health problems in children can be identified, as reported by parental perspective, they are expected to be mainly within the internalizing spectrum (Hy A21), only some significant results could be found. Means and standard deviations are reported in table 11. Thus, in case of ill mothers there was neither a significant difference between internalization and externalization scales (t(15) = 0.67, p > .05, single tailed, ns.) nor a significant effect (d = 0.21, small effect). The lack of a significant or in its effect size difference leads to the rejection of Hy A21 for this group. Nevertheless, in case of ill fathers the difference between internalization and externalization scales is significant (with t(20) = 1.73; p < .05 single tailed; d = 0.47) with the effect medium in range (in the following, Cohen's classification is used). Therefore, the Hy A21 being supported only by the data for the ill fathers it is partially confirmed even though result of the effect size (d = 0.21) in ill mothers group points into the assumed tendency.

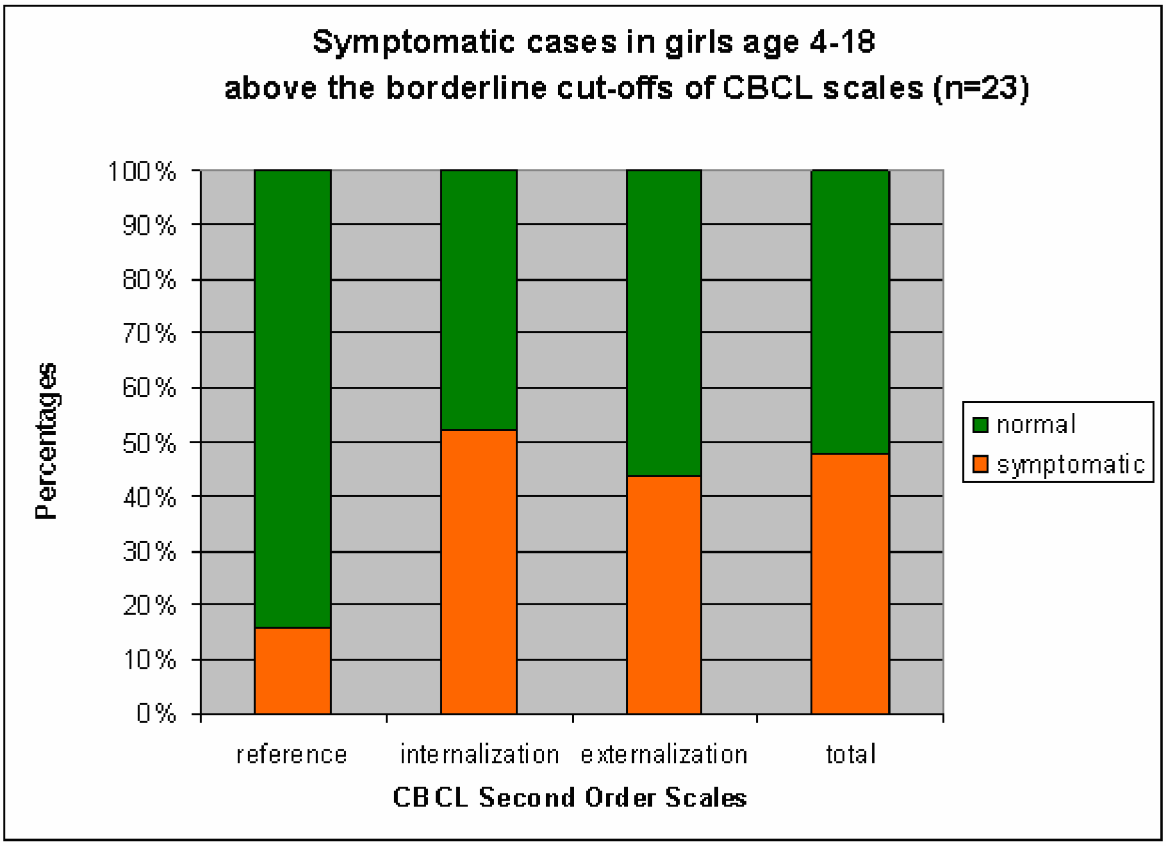

Figure 3. Prevalence of symptomatic children and adolescents (girls) in parents' reporting perspective (CBCL).

Table 11

Parents' perceptions of children and adolescents emotional and behavioural problems (CBCL) by ill parent's gender

M (SD)	Mother ill	Father ill
internalizing	58.87	58.61
	(6.63)	(7.52)
externalizing	57.50	55.04
	(6.12)	(7.49)
total	57.45	57.57
	(5.56)	(6.42)

Analysing the above data for significant difference due to ill parents' gender, no significant gender effect could be identified (for internalization scale t(35) = -.107, p > 0.5; ns.; for externalization scale t(35) = -1.06, p > 0.5; ns.; for total problems scale t(35) = .067, p > 0.5; ns.).

3.2.2 Adolescents' self – reporting perspective

Analogue to the previous way o analysis, YSR data on internalizing, externalizing and total problems were drawn upon regarding hypotheses Hy A1 and Hy A2 and the corresponding sub-hypotheses Hy A12 and Hy A22.

In the self-reporting perspective, the percentages of symptomatic cases (borderline cut-off) among boys between 11 to 18 years old were 16.66% for total problems, 27.77% for internalization and 11.11% for externalization symptomatology. Figure 4 shows the boy's symptom's prevalence's in the second order scales of the YSR. Total score problems were only slightly increased (16.66%) as compared to a reference population. The only notable difference was found in the internalization problems scale where percentages was almost double (27.77%) than the one in a reference population (16%).

As regarding the girls, the percentages of symptomatic cases (borderline cut-off) were 51.85% for total problems, 59.29% for internalization symptomatology, for both second-order scales more that three times higher than in reference population (16%), and 29.69 % for externalization symptomatology, almost double than in a reference population. Figure 5 shows the girl's symptom's prevalence's in the second order scales of the YSR. A comparison between the two gender groups revealed a much higher rate of symptomatic individuals among girls, tendency confirmed also by parental perspective.

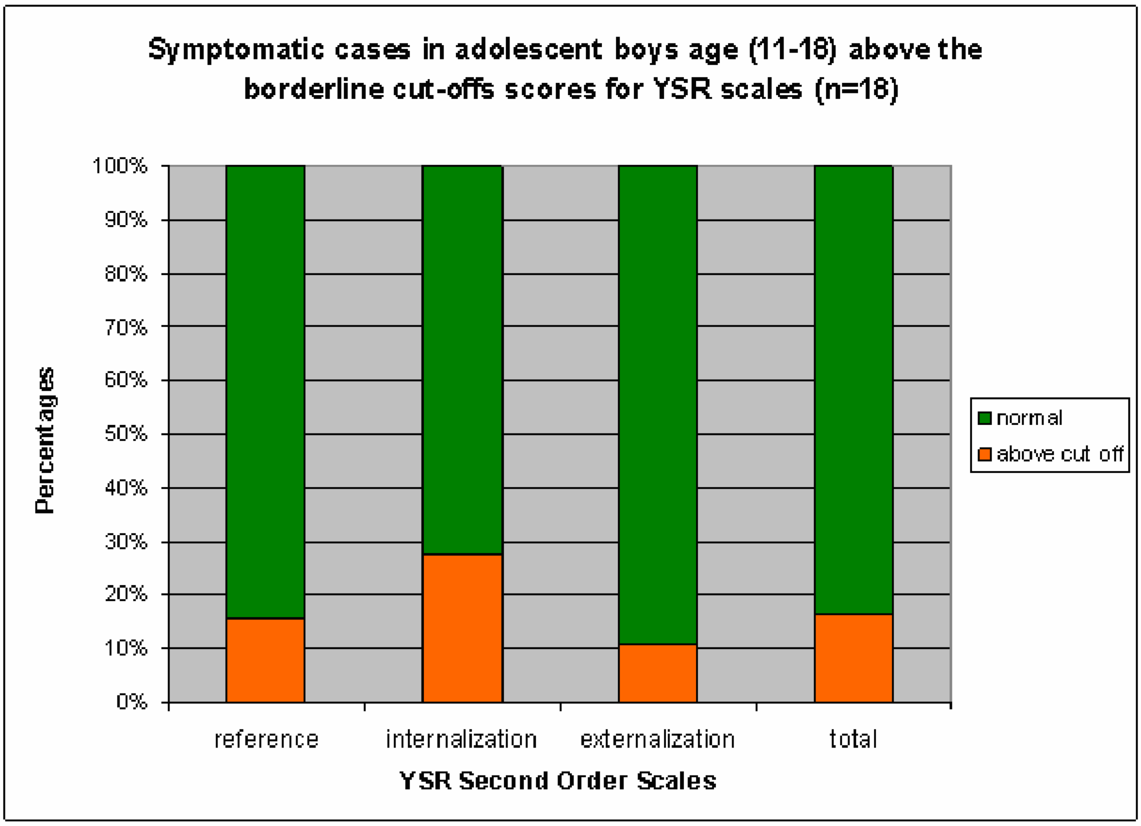

Figure 4. Prevalence of symptomatic adolescents (boys) in self-reporting perspective (YSR).

In this case (self-reporting perspective) the Hy A12 is not supported for the boy's group data. For this group the Hy A12 is confirmed only for internalization scale were the percentages of symptomatic cases is double time higher than in a reference population. However, for girls, the above results are more than sufficient to confirm the Hy A12, the percentages of symptomatic cases for all second order scales being at least double (internalization and total score even triple) as they are in a reference population. Therefore, for girls Hy A12 is confirmed.

Regarding the hypothesis that if some mental health problems in adolescents can be identified, as reported by self-perspective, they are expected to be mainly within the internalizing spectrum (Hy A22), the prevalent data show a significant difference between internalization and externalization scales and a medium size effect both for ill mothers (t(18) = 2.2; p < .02; d = 0.5 medium size effect) and for ill fathers (t(25) = 4.4; p < .00; d = 0.6 medium size effect) and therefore for this group of respondents the hypothesis Hy A22 is confirmed. All means and standard deviations are shown in table 12.

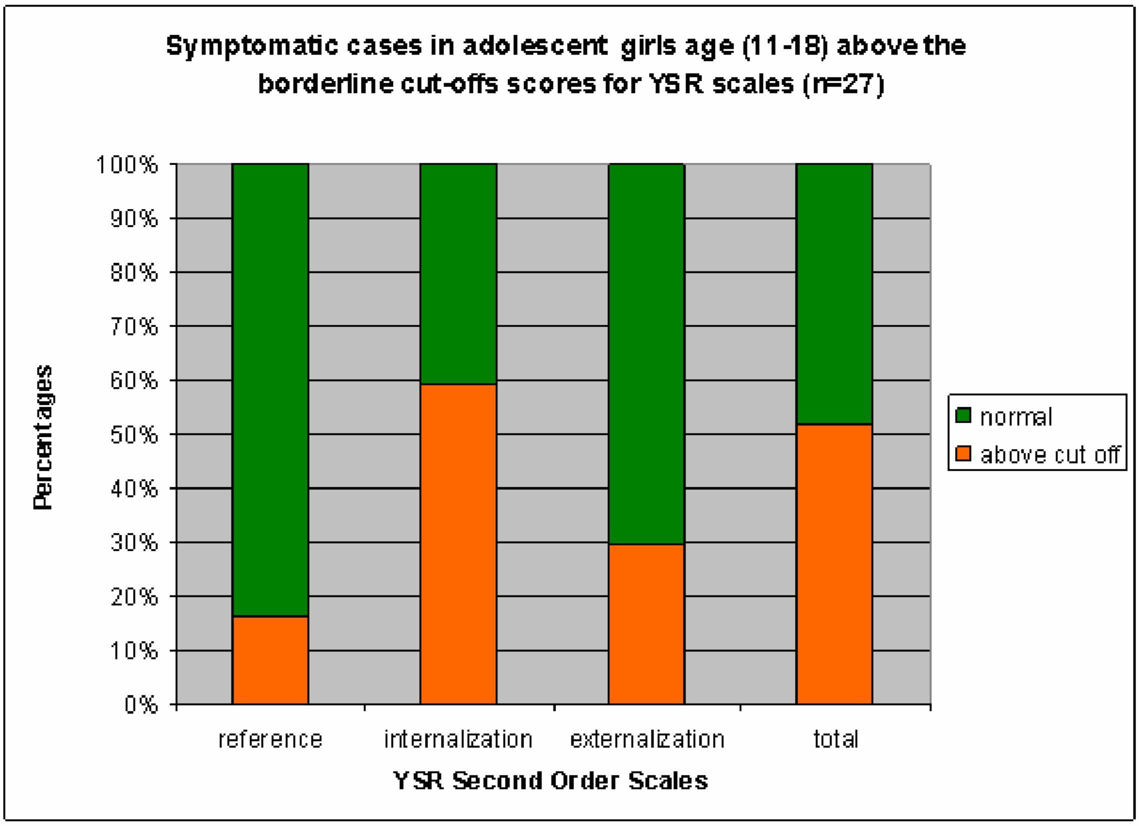

Figure 5. Prevalence of symptomatic adolescents (girls) in self-reporting perspective (YSR).

Table 12

Adolescents' perceptions of own emotional and behavioural problems (YSR) by ill parent's gender

M (SD)	Mother ill	Father ill
internalizing	57.00	61.38
	(7.70)	(8.95)
externalizing	53.00	54.96
	(7.17)	(10.57)
total	55.36	59.19
	(7.42)	(9.62)

Analysing the above data for significant difference due to ill parents' gender, no significant gender effect could be identified (for internalization scale t(43) = 1.71, $p > 0.5$; ns. ; for externalization scale t(43) = .699, $p > 0.5$; ns.; for total problems scale t(43) = .144, $p > 0.5$; ns.).

In sum, it was identified an increased psychopathology in children with an acute central nervous system injury parent as compared to a reference population, both from healthy parent perspective and from self-reporting perspective. Furthermore, prevalent data show a significant difference between internalization and externalization scales, pointing the fact that mental health problems in adolescents are mainly within the internalizing spectrum. Moreover, in an exploratory analysis, a comparison between the boys and girls revealed a much higher rate of symptomatic individuals among girls, tendency emphasized both from parental perspective and self-reporting perspective and no significant ill parent gender effect was found.

3.3 Question block B

In question block B, together with the goal of identification of mental health risk and protective factors for children with parents suffering of acute central nervous system injury (Q B1), it was tried also to determine if children problems are rather related to the depression of healthy parent or than to objective severity of the disease (Q B2).

In order to answer to research question Q B1 and to test the corresponding hypotheses (Hy B11 and Hy B12) and correspondent sub-hypotheses, as mentioned before, in a first step correlation between total problems scores of the YSR and various familial variables were calculated. The results are reported in table 13.

Table 13

Adolescents' correlation between total problem behaviour (YSR) and various personal and family variables

Correlation of YSR total problem (self-perspective) with…	Pearson correlation	Sig.	Cohen's effect size
Family dysfunction as a whole	.301*	.042	medium (0.6)
Family's dysfunction in clarity and acceptance of roles distribution	.303*	.041	medium (0.6)
Family's dysfunction in behaviour control	.239	.110	small (0.4)
Family's dysfunction in affective responsiveness	.319*	.031	medium (0.6)
Family's dysfunction in affective involvement	.331*	.025	medium (0.7)
Family's dysfunction in communication	.314*	.033	medium (0.6)
Family's dysfunction in problem solving	.247	.065	medium (0.5)
Healthy parent's health related quality of life (physical) - SF-8	-.357*	.027	medium (0.7)
Healthy parent's health related quality of life (mental) - SF-8	-.208	.165	small (0.4)
Healthy parent depression (BDI)	.334*	.023	medium (0.7)
Ill parent Karnofsky Index	.113	.459	small (0.2)

* Correlation is significant at the 0.05 level

Here, due to the fact that it was planned to look at a wide range of hypotheses using the YSR total problem as variable it appears necessary to take into consideration the Bonferroni correction. But, in spite of its simplicity (or perhaps because of it), the Bonferroni correction has attracted some criticism. Its biggest problem is that it is too conservative: by controlling the group-wise error rate, each individual test is held to an unreasonably high standard. One must be aware about the fact that, this can cause a substantial loss in the precision of the research findings (Simon, 2005), and thus reducing the power of the study (Perneger, 1998). If we do consider the Bonferroni correction for the above data, the significance level drop from 0.05 to 0.0055 which it is extremely low and all significant correlations will be lost. That's the reason why all correlations also were determined as effect sizes (d), whose largeness were estimated using Cohen's classification. Therefore, the above results will be presented both in light of significance and effect size (Sava, 2004).

In Hy B11 and the subsequent hypotheses (Hy B111 – Hy B116) I've investigated correlations referring to various aspects of family functioning. Here one must have in mind that, high scores of the FAD subscales stand for more pathology in family function.

Regarding Hy B11, a positive correlation was found (r = .301, p < .05) with a medium size effect (d = 0.6) between family dysfunction as a whole (example items: 51 "*We don't get along well together*"; 56 "*We confide in each other*") and psychological symptoms of children and adolescents. Therefore, Hy B11 is confirmed. In the following the correlations between subscales of FAD and psychological symptoms of children and adolescents will be investigated.

Thus, in Hy B111, the dysfunction in clarity and acceptance of the distribution of roles within the family (example items: 30 "*Each of us has particular duties and responsibilities*"; 45 *"If people are asked to do something, they need reminding*") were assumed to correlate positive with psychological symptoms of children and adolescents. In concordance with Hy B111, the results shows a positive correlation (r = .303, p < .05) with a medium size effect (d = 0.6), and consequently the Hy B111 is confirmed.

For behaviour control dysfunction within the family (example items: 55 "*There are rules about dangerous situations*"; 44 "*We don't hold to any rules or standards*"), Hy B112 refers to an expected positive correlation with psychological symptoms of children and adolescents. Even though the data point in this direction, the correlation is not significant (r = .239, p > .05; ns.), and the effect is small in size (d = 0.4). Hy B112 therefore has to be rejected.

As was expected, for the Hy B113, a positive correlation (r = .319, p < .05) was identified with a medium size effect (d = 0.6) between family dysfunction in affective responsiveness (example items: 49 “*We express tenderness*”; 28 “*We do not show our love for each other*”) and psychological symptoms of children and adolescents, supporting the previous stated assumption. Therefore, the Hy B113 is confirmed.

In Hy B114, family dysfunction in affective involvement (example items: 25 “*We are too self-centered”*; 5 “*If someone’s in trouble, the others become too involved*”) was assumed to correlate positive with psychological symptoms of children and adolescents, and the above results (table 14) shows a positive correlation (r = .331, p < .05) between the selected variables, with a medium size effect but extremely close to large effect (d = 0.7), in conclusion the Hy B114 is also confirmed.

Regarding dysfunction in communication within the family (example items: 43 “*We are frank with each other*”; 22 “*It is difficult to talk to each other about tender feelings*”), the correlation was positive and significant (r = .314, p < .05) and the effect was medium in size (d = .06), which means that, the higher the communication dysfunction the higher were scores for children psychological symptomatology. The supposition stated in Hy B115 is supported by the above data and it is confirmed.

Hy B116 refers to dysfunction in problem-solving within the family (example items: 2 “*We resolve most everyday problems around the house*”; 60 “*We try to think of different ways to solve problems*”) and expected that less functional problem-solving within the family to come along with high levels of psychological symptoms of children and adolescents. However, the correlation does not show a significant result (r = .247, p > .05; ns.) although the effect size was medium (d = 0.5). Even though the effect size point into the assumed direction, from a statistical point of view, the Hy B116 must be rejected.

Regarding the Hy B12 and its sub-hypotheses Hy B121 and Hy B122, well parent’s subjective appraisal of physical and mental health physical condition were measured by SF-8 healthy parent’s health related quality of life (physical) and SF-8 healthy parent’s health related quality of life (mental).

Hy B121 assumed that the healthy parent’s own, subjective appraisal of physical health correlates negative with psychological symptoms of children and adolescents, and this assumption is supported both by the correlation coefficient (r = -.357, p< .05) and by Cohen’s effect size (d = 0.7 medium effect size) which it’s right at the edge of large size effect (0.8). Therefore, Hy B121 is confirmed.
As for the mental health component summary (Hy B122), the data confirmed the assumed tendency (negative correlation), but the correlation it is not significant (r = -.208, p > .05; ns.), although the effect size (d = 0.4, small effect size) it is almost medium. So, the hypothesis Hy B122 has to be rejected.

Regarding research question Q B2 and its hypothesis Hy B21 and Hy B2, after the calculation of the requested correlation the following results have evolved. Consistent with Hy B21, higher scores of parental depression come along with high scores in children outcome, the results presented in table 14 showing a stronger positive correlation (r = .334, p < .05) and a medium effect (d = 0.7), which means that the healthy parent depression seems to play a big role for adolescents’ psychological outcome, therefore Hy B21 has to be confirmed.

Regarding the Hy B22 which stated that medical objective severity of the disease as measured by Karnofsky Index will positively correlate with psychological symptoms of adolescence as measured by YSR, the above results showed in table 14 did not support the previous stated hypothesis (r = .113, p > .05, ns.; d =

0.2 small effect). Therefore, between the objective severity of the disease and children's psychological outcome the correlation (even if it is positive) is extremely low, and statistically not significant, results supported also by a very small effect size. Therefore Hy B22 has to be rejected.

As mentioned in the previous section (2.3.6), in a second step, the results of the previous correlations were used to identify the set of variables, which could best predict psychological problems of children and adolescents through means of multiple regression analyses. Here one must be aware that the general principle of explanation is to seek the simplest powerful model (parsimony), and to avoid including variables that add virtually nothing to the predictive value of the model unnecessary complicate the model for negligible return, therefore one must limit the number of variables included in analysis (de Vaus, 2002). Apart from parsimony, the number of variables should be limited since increasing the number of variables artificially inflates the R^2 especially in small samples. As de Vaus mentioned (2002), the sample size is an important consideration when deciding how many variables to include in the model. The variable to case ratio helps identify the sample size required to accommodate the number of variables one wish to include. When all variables are entered into the model in a single block the ratio of cases to variable should be at least 20 : 1, and the minimum suggested sample to variable ratio is 5 : 1 (de Vaus, 2002). Taking into consideration the above conditions, it was decided to include in analysis only the variables which correlated significantly with psychological problems of children and adolescents (YSR total problems scale). For analyse it was choose the hierarchical strategy, starting with the variable having the highest correlation (Healthy parent's health related quality of life (physical) - SF-8), then adding one by one the other two predictors having the second, respectively the third highest correlation (Healthy parent depression – BDI and Family dysfunction as a whole – FAD). The following table 14 gives an overview on regression models used in hierarchical analysis.

Table 14

Summary of hierarchical regression analysis for variables predicting children and adolescents psychological symptoms (n = 43)

Variable	R^2	Adjusted R^2	F	Sig.	B	β	t	Sig.
Model 1	.106	.085	5.20	.027				
Healthy parent’s health related quality of life (physical) - SF-8					-.720	-.325	-2.28	.027
Model 2	.144	.105	3.63	.035				
Healthy parent’s health related quality of life (physical) - SF-8					-.466	-.211	-1.29	.204
Healthy parent depression (BDI)					.709	.228	1.39	.170
Model 3	.211	.155	3.75	.018				
Healthy parent’s health related quality of life (physical) - SF-8					-.426	-.193	-1.21	.232
Healthy parent depression (BDI)					.656	.211	1.32	1.92
Family dysfunction as a whole					.626	.260	1.88	.066

Thus, Model 1 shows that healthy parent’s health related quality of life (physical) accounts for 10% of the variance for children and adolescents in psychological symptoms (with R^2 = .106). The model showed to be significant with F = 5.20 ($p < .05$). When adding the second predictor – healthy parent depression– in Model 2, R^2 increase a little (R^2 = .144), but this is not just an effect of the integration of another variable because also the adjusted R^2 increase (from .085 to .105). Again the model is significant with F = 3.63 ($p < .05$), which means that, healthy parent’s health related quality of life (physical) combined with healthy parent depression stands for 14% of the variance for children and adolescents in psychological symptoms. In model 3, after taking into account the last predictor selected for analysis (family dysfunction as a whole), the previous identified trend continues with an increasing of the R^2 (from .144 to .211). Moreover, this is again supported also by an increasing in adjusted R^2 (from .105 to .155). Model 3 it is also significant with F = 3.75 ($p < .05$), therefore, healthy parent’s health related quality of life (physical), healthy parent depression and family dysfunction as a whole accounts for 21% of the variance for children and adolescents in psychological symptoms.

In sum, the attempt of identifying to identify the set of variables, which could best predict psychological problems of children and adolescents was valuable, the results pointing at the previous selected variables - healthy parent's health related quality of life (physical) (SF-8), healthy parent depression (BDI) and family dysfunction as a whole (FAD).

However, it was considered correct and necessary to make an analysis also with the highest correlation from FAD subscales – affective involvement, instead of family general functioning. Table 15 shows the corresponding models. The second regression analysis provide extremely useful information, and shows that, healthy parent's health related quality of life (physical) - SF-8, together with healthy parent depression – BDI, and family dysfunction in affective involvement subscale – FAD stands for 47% of the variance for children and adolescents in psychological symptoms, which is more than double than in the previous regression analysis.

Table 15

Summary of hierarchical regression analysis (with affective involvement; n = 43)

Variable	R^2	Adjusted R^2	F	Sig.
Model 1	.325	.106	5.20	.027
Healthy parent's health related quality of life (physical) - SF-8				
Model 2	.380	.144	3.63	.035
Healthy parent's health related quality of life (physical) - SF-8				
Healthy parent depression - BDI				
Model 3	.477	.288	4.12	.012
Healthy parent's health related quality of life (physical) - SF-8				
Healthy parent depression - BDI				
Family dysfunction in affective involvement – FAD				

3.4 Pilot intervention study - Question block C

Regarding the question if children’s detectable stress reactions as measured by psychological symptoms change over time after the traumatic event (Q C2), both parental (CBCL) and self-reporting (YSR) perspective were analysed. Thus, for testing the Hy C11 which assume that the level of somatic complaints will increase after the ill parent returns home due to the increase exposure to stressful stimuli, in a longitudinal approach, it was compared the time evolution of total problems scale scores from CBCL and YSR. As it was mentioned before, the data were collected at the beginning of the intervention (t0 – initial evaluation), after one month (t1 – intermediary evaluation) and after sixth months (t2 – final evaluation). Table 16 shows the corresponding means and standard deviations. Here one must be aware that only data from the counselling group were analysed, the control group being evaluated only at the beginning (t0) and after 6 months (t2).

Table 16

Course of CBCL and YSR total problems scores over time

M (SD)	t0 (n = 27)	t1 (n = 27)	t2 (n = 27)
CBCL total problems	59.17 (7.20)	57.00 (13.47)	55.45 (8.37)
YSR total problems	59.81 (10.00)	58.43 (8.54)	56.63 (8.07)

Here, opposite to expectations, the results show a continuous decrease of total problems scales scores both from parental perspective (CBCL) and self-report perspective (YSR). Thus, the assumption in Hy C11, which expected an increased score for intermediary evaluation (t1) after the ill parent returns home can not be supported and leads the according hypothesis, has to be rejected. But, as mentioned before, one must be aware that the above analysis was made only with the intervention group and that they have received 4 counselling sessions during this 6 month period.

Regarding research question Q C2 and the corresponding hypothesis Hy C21 which stated that “face-to face” interventions through counselling sessions are more effective in reducing children’s stress symptoms than written advices and recommendations by a brochure, methodological issues placed some difficulties in setting up a good analytic strategy. First, after the comparison of total problems score (both CBCL and YSR) between these two groups it was found that their initial status were not as similar as it had been expected in a randomised distribution. All means and standard deviations are shown in table 17. But, after a careful analysis it was noticed that the observed differences were not statistically significant, neither for CBCL (t(36) = -1.46, p > .05; ns.), with small effect size (d = 0.4), nor for YSR (t(44) = 1.82, p > .05; ns.), however the effect size was medium (d = 0.5). These data allow going further with the previous mentioned steps (see 2.2) in verifying Hy C21 with some modifications in the analytic strategy.

Table 17

Total problems scale score (CBCL and YSR) comparison between intervention and control groups

M (SD)	Intervention group		Control group	
	CBCL	YSR	CBCL	YSR
Total problems score	58.95 (6.74)	59.83 (9.85)	56.16 (4.66)	55.22 (7.32)

Anyway, due to the fact that their initial status was not similar and also because the aim was to asses the time evolution only of those having problems, for measuring intervention effects, were included in analysis over time, only the cases which scored above the cut-off score, and therefore could be defined as symptomatic. Following the same longitudinal approach, time evolution of total problems scale scores from CBCL and YSR data from intervention group were compared with the corresponding data from the control group. Second, the factors contributing to a better or less good evolution of the children after the psycho-trauma of an acute severe somatic parental illness are complex. The problem is, if the “therapeutic effects” can be discriminated from a spontaneous good evolution of the child related to time, to a faster recovery of ill parent or to factors of resilience as good family coping mechanisms.

Knowing that the above comparison will not be sufficient for discrimination of the therapeutic effects from a good spontaneous evolution (and also being aware that this was a risky approach), the introduction of tests for subjective therapeutic satisfaction (Mattejat & Remschmidt, 1993; Mattejat, 1997) for those who have received an intervention, became a necessity. The comparative analysis and corresponding results are presented in table 18 for parental reporting perspective and in table 19 for self-reporting perspective. Thus, from parental perspective, for the intervention group, the above results shows a decrease in total score problems from t0 (initial evaluation) to t2 (final evaluation after 6 months), even though the difference is not statistically significant (t(9) = 1.63, p > .05; ns.). But, having an almost large effect size (d = 0.7) these results emphasize a tendency according to which those receiving counselling have had a good evolution over time.

Table 18

Parental perspective comparison between intervention and control groups

M (SD)	Intervention group		Control group	
	CBCL (n = 10)		CBCL (n = 5)	
Total	t0	t2	t0	t2
problems	64.10	61.40	62.00	62.80
Scale	(2.37)	(4.47)	(1.41)	(1.92)
Cohen’s effect size	d = 0.7 medium		d = -0.4 small	

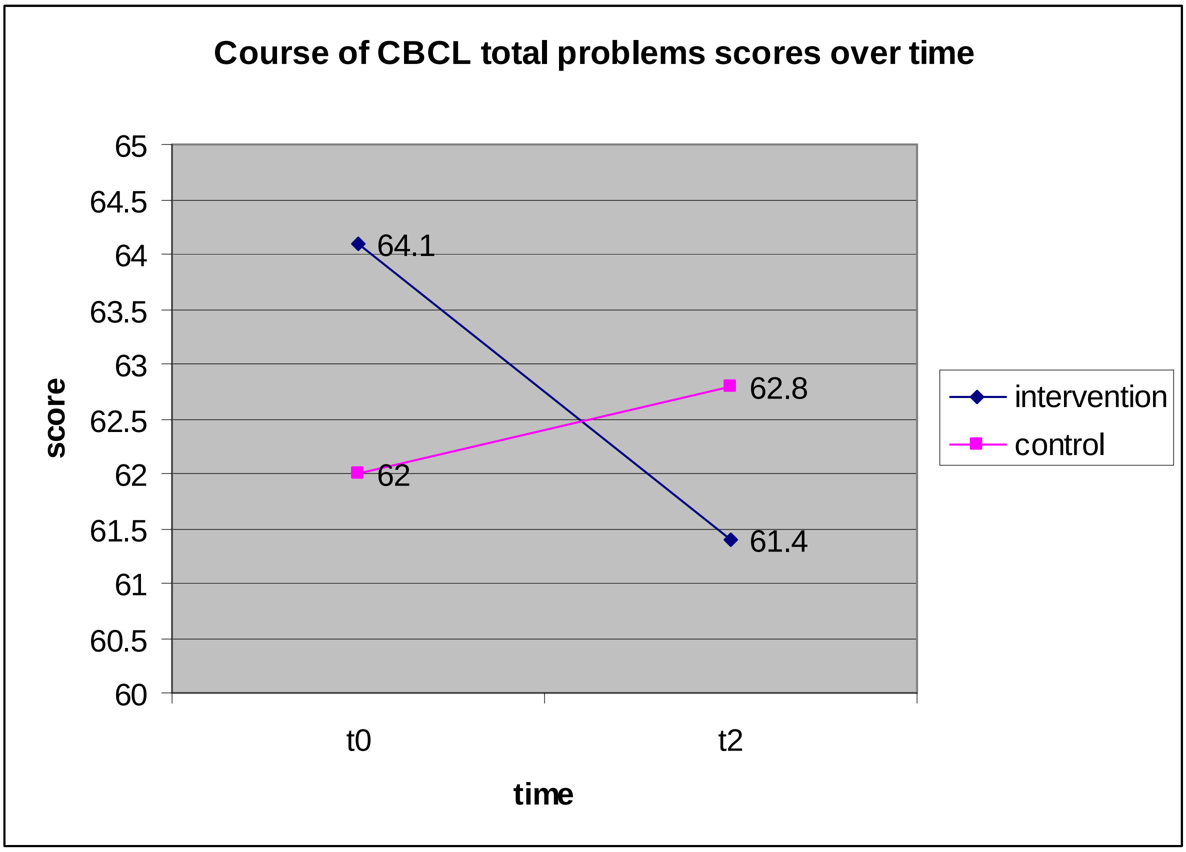

Figure 6. Course of intervention and control groups CBCL total problems scores over time

As for the control group, no amelioration of total score problems was found, on the contrary the results show a slightly increasing of total problems scale score, but this is almost insignificant (t(4) = 1.37, p >.05; ns.; d = -0.4 small effect size). Therefore, from parental perspective, the Hy C21 is confirmed, although the results were supported only by effect size. Figure 6 shows in a more suggestive way the evolution over time of both intervention and control group.

From self-reporting perspective, the results presented in table 19 show for both experimental groups a decrease of total score problems. The total problems score in intervention group significantly decrease from t0 to t2 (t(8) = 3.05, p < .05), having also a medium (almost large) effect size (d = 0.7). Again, for the intervention group, the previous mentioned tendency (those receiving counselling have had a good evolution over time) was confirmed by the above data, in the self-reporting perspective the difference being statistically significant.

Table 19

Self-reporting perspective comparison between intervention and control groups

M (SD)	Intervention group		Control group	
	YSR (n = 9)		YSR (n = 7)	
Total	t0	t2	t0	t2
problems	67.66	60.44	64.28	59.28
Scale	(11.14)	(9.28)	(4.27)	(6.92)
Cohen's effect size	d = 0.7 medium		d = 0.8 large	

Regarding the control group, the results show also a decrease in total problems score over time, but the difference between t0 and t2 is not statistically significant (t(6) = 1.99, p > .05; ns.), even though the effect size is large (d = 0.8). Here it was observed a different pattern from parental reporting perspective where the results showed a static situation. In this case, from self-reporting perspective, the results are in concordance with the Hy C21, both from effect size and significance test analysis. Therefore, for self-reporting perspective, the Hy C21 is confirmed. Figure 7 present the YSR total problems score evolution over time for both intervention and control group.

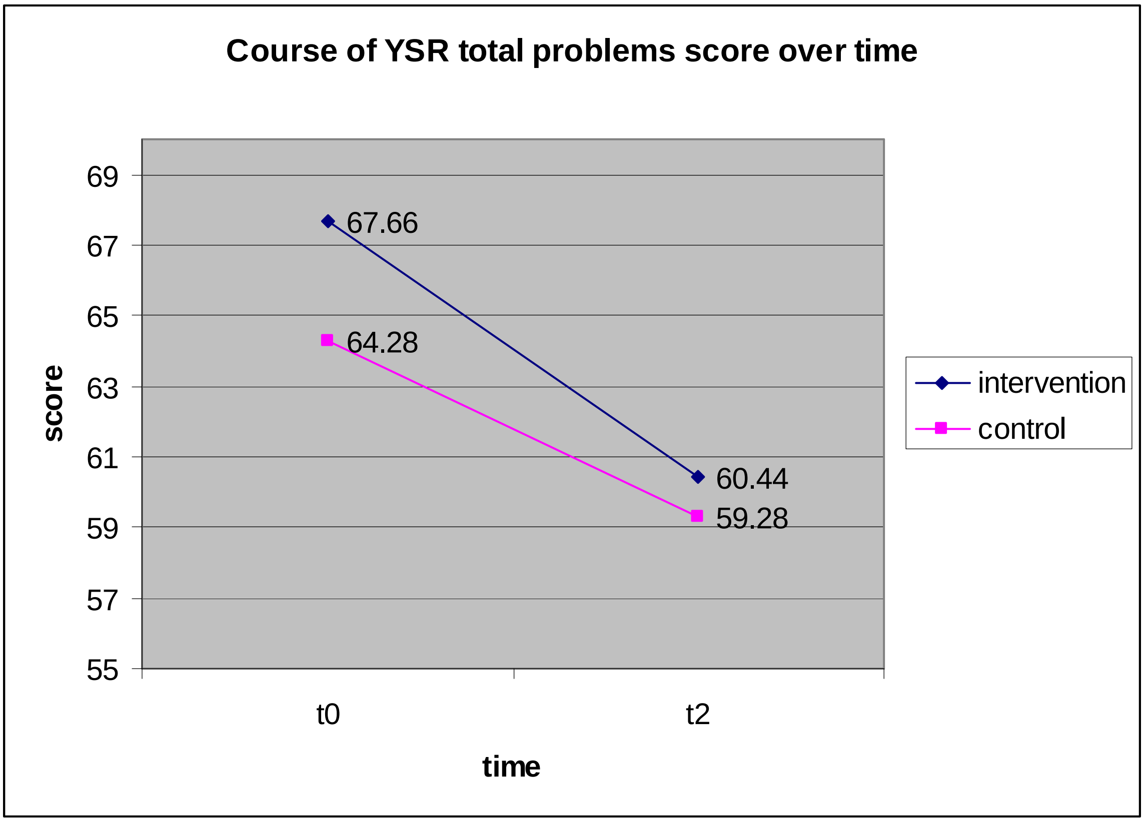

Figure 7. Course of intervention and control groups YSR total problems scores over time

In order to go one step further and somehow to double-check the above findings, the internalization and externalization scales scores were analysed concerning their evolution over time for both experimental groups (intervention and control). The comparative analysis and corresponding results are presented in table 20 for parental reporting perspective. Thus, from parental reporting perspective, for the intervention group, the above results shows a decrease both for internalization problems scale (t(9) = 1.60, p >.05; ns.; d = 0.4 small effect size) and for externalization problems (t(9) = 0.87, p > .05; ns.; d = -0.2 small effect size), although the differences are not statistically significant.

Table 20

Parental perspective internalization and externalization scales comparison

M (SD)	Intervention group		Control group	
	CBCL (n = 10)		CBCL (n = 5)	
	t0	t2	t0	t2
Internalization problems scale	65.50 (5.42)	62.80 (6.56)	57.80 (4.43)	58.60 (3.91)
Cohen’s effect size	d = 0.4		d = -0.2	
	t0	t2	t0	t2
Externalization problems scale	60.90 (4.14)	59.10 (5.95)	63.00 (2.23)	64.00 (3.39)
Cohen’s effect size	d = 0.3		d = -0.3	

For the control group, the situation is other way round, here both internalization problems scores (t(4) = 0.82, p > .05; ns.; d = 0.3 small effect size) and externalization problems scores (t(4) = 1.29, p > .05; ns.; d = -0.3 small effect size) showing a slightly increase over time. The above results are congruent with the previous findings regarding the total problems score evolution over time for both analysed groups.

From self-reporting perspective, the results showed in table 21, reveal the previous discovered tendency, thus of decreasing of total problems scores over time, both for the intervention and for control group. Analysing the intervention group data, it was discovered that only the internalization scale score the effect size of the decreasing was large (d = 1.0) even though the statistical significance was at the edge of significance (t(8) = 2.19, p >.05; ns.; p=0.6). For the externalization problems scale, the tendency was confirmed but the decreasing was not statistically significant (t(8) = 2.01, p > .05; ns.) with a small effect size (d = 0.3). Regarding the control group, the results are also in concordance with previous findings (total problems score), both internalizing problems scale (t(6) = 1.54, p > .05; ns.) and externalizing problems scale (t(6) = 1.38, p > .05; ns.) scores decreasing from t0 to t2, but again (as for the parental reporting perspective) for this group the differences are not statistically significant. Still, a medium effect size was found for both scales (internalization (d = 0.5) and externalization problems (d = 0.7)).

Table 21

Self-reporting perspective internalization and externalization scales comparison

M (SD)	Intervention group		Control group	
	YSR (n = 9)		YSR (n = 7)	
	t0	t2	t0	t2
Internalization problems scale	68.88 (10.19)	60.33 (6.46)	65.14 (6.01)	61.57 (7.20)
Cohen's effect size	d = 1.0		d = 0.5	
	t0	t2	t0	t2
Externalization problems scale	62.55 (14.50)	58.00 (8.29)	59.14 (2.73)	56.00 (5.80)
Cohen's effect size	d = 0.3		d = 0.7	

But, as it was mentioned before, those results must be approached with caution because the intervention effects can hardly be discriminated from a spontaneous good evolution of the child related to time, to a faster recovery of ill parent or to others factors of resilience, and also because the analysed sample is relatively low. In order to validate in a way the above results regarding the evolution of intervention group, the tests for subjective therapeutic satisfaction was used (Mattejat & Remschmidt, 1993; Mattejat, 1997) for those who have received an intervention. Figure 8 show the corresponding scores from different reporting perspective.

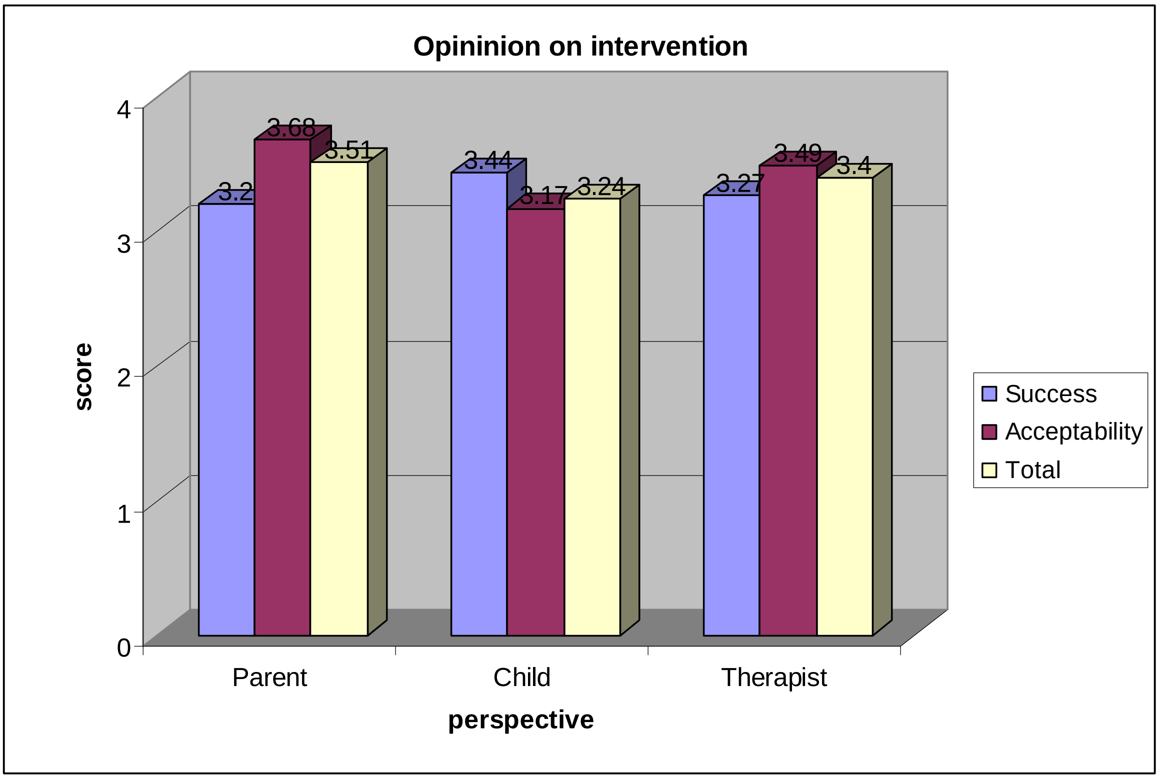

Figure 8. Different perspective regarding opinion on intervention

The tests of therapeutic satisfaction confirmed quality of intervention through high scores of success and acceptability recorded by all participants (child, parent and therapist). The differences between different reporting perspectives were small. Table 22 shows the meaning of the above scores.

Table 22

Opinion on intervention scores significance

Success of intervention		Acceptability of intervention	
4	completely successful	4	very good acceptability
3	predominantly successful	3	good acceptability
2	partly successful	2	moderate acceptability
1	predominantly ineffective	1	little acceptability
0	completely ineffective	0	no acceptability

Children appreciated most the success of the intervention, confirming in this way the above results which proved that their level of symptomatology as measured by YSR second order scales, decreased over time. Parents' considered the acceptability of therapeutic relationship being at first. This is somehow in concordance with the previous results, where, from parental perspective (CBCL second order scales) no statistically significant decreasing of scores was reported. The therapists reported high scores both on acceptability and success which is similar to parents and also with children opinion, their direct beneficiary, and therefore represent the best validation one can expect.

In sum,

- it was identified an increased psychopathology in children with an acute central nervous system injury parent as compared to a reference population, both from healthy parent perspective and from self-reporting perspective;
- prevalent data show a significant difference between internalization and externalization scales, pointing the fact that mental health problems in adolescents are mainly within the internalizing spectrum;
- in an exploratory analysis, a comparison between the boys and girls revealed a much higher rate of symptomatic individuals among girls, tendency emphasized both from parental perspective and self-reporting perspective and no significant ill parent gender effect was found;
- family dysfunction as a whole positively correlate with psychological symptoms of children and adolescents;
- besides the general functioning subscale, four sub dimensions of family functioning predicted children's problems, namely affective responsiveness, affective involvement, roles and communication;
- higher scores of parental depression come along with high scores in children outcome;
- medical objective severity of the disease as measured by Karnofsky Index did not predict children's psychological outcome;
- the set of variables, which could best predict psychological problems of children and adolescents are healthy parent's health related quality of life

(physical) (SF-8), healthy parent depression (BDI) and family dysfunction as a whole (FAD);

- however, a secondary regression analysis showed that healthy parent's health related quality of life (physical) - SF-8, together with healthy parent depression – BDI, and affective involvement subscale – FAD stands for 47% of the variance for children and adolescents in psychological symptoms;
- it was revealed a tendency according to which those receiving counselling intervention have had a good evolution over time;
- "face-to face" interventions through counselling sessions seems to be more effective in reducing children's stress symptoms than written advices and recommendations by a brochure;
- tests of therapeutic satisfaction confirmed quality of intervention through high scores of success and acceptability recorded by all participants (child, parent and therapist).

4. Discussion

4.1 Prevalence and types of psychological problems in children of parents with CNS injury

In this study, 58 families with acute central nervous system injured parent were examined for children's and adolescents' psychological symptoms. In a first approach, children of acute central nervous system injured parents were compared to a reference population, to investigate whether they show more symptoms than controls.

The psychopathology of family members, especially of children, exposed to the family stressors associated with acute central nervous system injury of one parent is few discussed in the literature (Buzell, 1994; Marsh, Kersel, Havill, et al., 1998; Finney & Miller, 1999; Curtiss, Klemz & Vanderploeg, 2000), although the traumatic dimensions are highly impressive: a dramatic life threatening event with heavy symptoms (Rolland, 1987) which is usually followed by an unforeseen evolution, with possible later appearance of chronic defective personality changes. For the family, beside the initial emotional turmoil, expressed by depression and anxiety, very soon heavy tasks of care appear. Sometime they represent a great burden which can overwhelm the family (Glick, Clarkin & Kessler. 1987; Johnson, 2000; Knight, Devereux & Godfrey, 1998; Powell, 2001).

As a family member, the child is substantially involved in family processes initiated by parental illness: disorganization, role changes, re-division of family tasks and reorganization (Leathem, Heath & Woolley, 1996; Kosciulek, 1997; Powell, 2001). In the parental reporting perspective, the prevalence of relevant psychological problems in our sample of children exposed to serious parental illness was almost three times as high as in a reference population. Thus, for internalization problems exceeding for more than three times (for girls) and more than two times (for boys) the reference population, and for externalization problems also almost three times higher (for girls) than in a reference population. Furthermore, an increased level of symptomatology in girls as compared to boys was found. Equally, in the self-reporting perspective, the percentages of symptomatic cases (borderline cut-off) was more than three times higher than in a reference population for girls, both for general problems and for internalization symptomatology, almost double for externalization symptomatology, than in a reference population. For boys, the only notable difference was found in the internalization problems scale where percentages was almost double than the one in a reference population. As mentioned before (also from parental reporting perspective) the comparison between the two gender groups revealed a much higher rate of symptomatic individuals among girls. Before distinguished interpretations can be elaborated, which go beyond the commonplace cliché of girls' proneness towards internalizing symptom formation, further analyses are needed. (Romer, Kienbacher, Milea et al., 2005). In conclusion, the hypothesis that children and adolescents of acute central nervous system will present an increased psychopathology as compared to a reference population was confirmed.

The hypothesis that children's symptoms would be more prominent as internalizing problems was also clearly confirmed, the prevalent data showing a significant difference between internalization and externalization scales. This finding reflects the prevalence of disorders in the inner emotional field expressed by a higher score on internalization scale in comparison with externalization scale both for the parental reporting perspective and the self-reporting perspective, and also both for boys and girls. The increased risk for internalizing problems among children of somatically ill parents, especially for anxiety and depression, replicates the findings in other empirical studies on children of parents with other somatic diseases (Compas, Worsham, Epping-Jordan et al., 1994; Compas, Worsham, Ey et al., 1996). Anxiety and depression as clinically relevant symptom clusters can be understood as natural "extensions" of fear, sadness or grief, which are adequate emotional reactions in a child facing a seriously ill parent who is suffering and whose prognosis may be insecure or even terminal (Barkmann, Romer & Schulte-Markwort, 2006). With regard to the particularly increased scores of somatic complaints, both the parental model of being physically harmed, that defines the legitimacy for the entire family's attention and sympathy, as well as an unconscious overly identification with the ill parent and his or her physical condition are likely to contribute to this situation (Romer et al., 2005). These data are important for understanding children's reactions to serious life crises like parental illness (Birenbaum, Yancey, Phillips et al., 1999; Finey & Miller, 1999; Graham, Turk & Verhulst, 1999; Romer et al., 2002). Previous findings underlined the importance of anxious depressive symptoms in expressing the process of loss and mourning; feelings of insecurity, sadness and helplessness (Riedesser & Fischer, 2001).

In sum, our results confirm that children of parents affected by central nervous system injury are at an increased risk for mental health problems, even more within the internalizing spectrum. This is evidenced both from the healthy parent's perspective and from the self-reporting perspective. These results are in accordance with a previous study, showing that intrapsychic criteria or symptoms within the internalizing spectrum reflect the child's mental health problems (Steck, Grether, Amsler et al., 2005).

4.2 Associated predictive factors

Regarding the question if children problems are rather related to the depression of healthy parent or to objective severity of the disease, the somatic illness is viewed as a severe negative life event. As mentioned before, comprehensive care of the person with acute central nervous system injury involves the entire family. Psychological distress affects not only the chronically ill patient but also the caregiver (Keller & Henrich, 1999). Somatic, anxiety and depressive symptoms are common in these caring partners, and it is important for the professional healthcare team to recognize these symptoms and provide appropriate support (Knight, Devereux & Godfrey, 1997). Parents often have difficulties in acknowledging the effect of the illness on children. False perceptions could possibly prevent children and adolescents from receiving appropriate mental health interventions (Heiney, Bryant, Walkers et al., 1997). The parental attention was mainly focused on the state of ill conjoint with neglect of other member of family including themselves. However, we consider that as in other chronic illness (Barnes, Kroll, Burke et al., 2000) healthy parents introduced some filters for protection of their children in content of information with the intention to offer a supportable image of conjoint illness in spite of its severity. The acute illness was presented as the unexpected negative life-event, being censured in its dramatic aspects as coma, paralysis and admission in the intensive care ward. In some families it was created a true ”conspiracy of silence” (clinical impression during the counselling intervention). That can explain in a way the lack of correlation between the severity of illness measured by Karnovsky Index and children and adolescents psychological outcome.

In the current study correlation analysis revealed that, the higher the depression scores of healthy parents, the higher is the level of psychological symptomatology in their children. Steele, Forehand & Armistead, (1997) in their studies reported that parental illness impacts child internalizing symptoms. In children, the perception of severity of an illness depends not only from the cognitive content of information delivered by adults but also from their emotional (Anderson & Hammen, 1993; Kreutzer, Gervasio & Camplair, 1994). The depression of the healthy parent as measured by the BDI was found to predict psychological symptoms of children and adolescents. It seems that if the healthy parent does not become depressive he/she gives the child a message that the serious situation can be dealt and coped with somehow, whereas if the healthy parent reacts with depression himself/herself the message for the child is helplessness. In contrast, maintaining emotional balance in critical moments of life get a protective factor offered by parent for his offspring mental health (Romer et al., 2005).

Numerous studies (Sameroff, Seifer, Zax et al., 1987; Sameroff, Seifer, Zax et al., 1992; Seifer, Sameroff, Baldwin et al., 1992) indicate that the quality of the emotional availability of the healthy parent may compensate for the inattentiveness of the ill parent. The child’s significant relationship with compensatory caregiver(s) may be a key variable that allows the child some respite and perhaps even some escape from risk (Davies, 1994; Drotar, 1994; Lewis, Woods, Hough et al., 1989). Bad moods, resignation or even desperation in a seriously ill parent may be perceived by a child as states that belong to the parent’s situation of being seriously ill, which already imposes distress on the child. When a child has to cope with the image of a harmed and weakened parent, or even with the threat of his or her death, the secure base previously offered by this ill parent is existentially questioned (Romer et al., 2005). This calls for a well-functioning healthy spouse who has to represent the solely remaining compensatory parental object to lean upon for comfort. In this, an undisturbed emotional availability of the healthy parent as a secure base for the child seems to be a crucial protective factor (Bowlby, 1988), which is absent, if the healthy parent is depressed. The above data mirrored the image of family reactions for some illnesses as cancer (Anderson & Hammen, 1993; Kreutzer, Gervasio & Camplair, 1994; Birenbaum, Yancey, Phillips et al., 1999; Goodman, Brown, Cloitre et al., 2002; Romer et al., 2002; Edwards, Watson, St. James-Roberts et al., 2006).

Regarding the family variables and family functioning, one could easily observe that, the quality of intrafamilial relationships is an important missing link in the mechanisms involved that explains how exposure to stress in families may or may not lead to psychological problems in children (Romer et al., 2002). If a family develops adaptive coping strategies, these serve as a model for the individual child’s psychological adaptation. Based on these assumptions, high family functioning was considered protective for children exposed to parental physical illness, whereas family dysfunction may be likely to predict children’s maladjustment respectively. The new situation can be considered as one of family crisis which bears to major disorganizations of the routines, and huge increase of emotional tensions between the healthy family members. Thus the child’s psychosocial development is supposed to be affected by secondary effects of a parent’s illness on family life, such as fears for the future, financial burdens, role changes, physical strains of caring, or marital distress as well as on the parent-child relationship in particular, such as changes in parental personality traits, parents' self-esteem, emotional availability for, parenting competencies, as well as separations due to hospitalisation or anticipated loss (Lewandowski, 1992; Romer et al., 2002).

The results show that discrepant levels of family functioning predicted children's psychological symptoms. This is supported by the positive correlation between family dysfunction as a whole and children and adolescents psychological symptoms. Furthermore, the finding that, besides the general functioning subscale, mainly dysfunction in four other sub dimensions of family functioning predicted children's problems, namely affective responsiveness, affective involvement, communication and roles, deserves more in-depth interpretation. As it was mentioned before, affective responsiveness refers to family members' open sharing of feelings, whereas affective involvement reflects interest and value family members attach to each others' activities, communication involving honesty, difficulty and level of communication between family members and roles refers to clarity and acceptance of roles distribution, to particular duties and responsibilities. Present findings suggest that teenage children's healthy adaptation to illness-related family stress is facilitated if parents and children are able to express and share feelings openly while maintaining appropriate boundaries between individual family members that help to prevent over-involvement with each other, if they are able to communicate open to each other and to share and also accept specific new roles and responsibilities. Furthermore, open communication about illness-related concerns and related feelings should be facilitated in order to prevent a conspiracy of silence. These findings may well inform focused intervention concepts in medical family therapy.

Those findings are supported by similar results from previous studies. Thus, Rost (1992) in his review on empirical studies on children of somatically ill parents summarized some protective factors, such as open communication between parents and children about the illness as well as flexible boundaries between the family system and the social environment. Following the same idea, Power (1985), find that well adjusted families were those in which family members took care of own needs and were involved in activities outside the family. Furthermore, communication about the disease was open and information of all family members was appropriate. On the other side, in the poorly adjusted families, the disease was perceived as an ongoing source of distress. Lack of communication, information and understanding was prominent in these families. Correlation analyses revealed that only two of the FAD subscales did not correlate with children and adolescents psychological symptoms, namely behaviour control and problem solving. Here, one can assume that by the very nature of the traumatic event and its consequences for family life, all families will have to make use of their resources and skills in problem solving and behaviour control to a maximum degree. Therefore, these two areas of family function are highly activated in terms of primary coping requirements.

Also the regression analysis performed showed that, among all factors tested as associated variables predicting risks for psychological problems in children of acute central nervous system injury parents, the current state of family functioning in this stressful life situation, together with healthy parent depression and healthy parent's health related quality of life (physical), had the clearest predicting power. However, by introducing in analysis the highest correlation from FAD subscales – affective involvement, instead of family general functioning, the model become even more efficient, pointing the fact that affective involvement is extremely important for children's and adolescents' adjustments.

The findings presented here indicate that family functioning, healthy parents' depression and healthy parents' health related quality of life (physical), plays a more crucial role for children's adaptation to serious parental illness than other parameters examined, such as healthy parents' health related quality of life (mental), ill parents' gender or the severity of the ill parents' impairment. This is an important finding, as family functioning as a variable can be influenced by family-oriented psychosocial interventions (Romer et al., 2005). Medical parameters, although representing the main cause of family stress in this particular life situation, seems not to play such an important role.

4.3 Pilot intervention study

4.3.1 Context derived specific recommendations

The access to children and families with a parent hospitalised for acute central nervous system injury, normally involved the family's agreement. The problems we faced at this level are not to be neglected by those who want to provide prophylactic intervention services in this field, and they were expressed by the unexpectedly large percent (60%) of refusals. The refusal to accept our offer was not caused only by the fact that the community was not familiar enough with the preventive assistance for mental problems, but also by objective factors, which distinguish our study from those addressing children and families having a parent affected by chronically somatic diseases. Such factors are a consequence of:

- the fact that we addressed cases in which the affection of one parent had an acute nature, with an unexpected appearance. On the one hand, this involves an immediate vital danger, which is dominant and hopefully will have favourable evolution and not the other way round, and on the other hand, the fact that one of the parents is affected suddenly disturbs the family's life style in a negative way. All these features unexpectedly re-structured the family's priorities and focused them on the new problem (which meanwhile became the major problem). This can diminish the family's interest in potential subsequent risks, especially in preventive measures;
- the precocious nature of the intervention, which is established while the affected parent is still in the hospital, a period dominated by the momentary difficulties.
- These features may explain somehow, why 58% of the families explained their refusal by phrases such as "we don't have time now for such problems" – the medical staff we tried to involve in the study providing similar arguments. Also, a

so-called “spiral of silence”, so often adopted by the parents who did not want to involve the children in their problems was the reason why 36% of the families did not agree to participate in our study when they were told that it will involve discussions with children. Almost half of them emphasized: “all our problems will be solved and our children will be then protected”. The “spiral of silence” also functioned when we requested to contact the school, none of the families expressed their agreement to our involvement. Also, the request to sign an informed consent form, as official acceptance of our services was perceived by Romanian families with suspicion, as a doubtful action involving hidden risks or constraints, and not as an ethical approach ensuring the exertion of the legal rights for protection.

From the perspective of the future implementation in Romania of a service with such profile, it is necessary to take into consideration some significant peculiarities:

- the reminiscences of a long period of marginal placement of psychology, mental health and psychotherapy and related topics as it was already mentioned, demand much efforts for persuading the families to accept the help offer and the specialists from other medical professions to cooperate in for delivery of such services;
- the fact that in Romania, families and children having an acute central nervous system injured parent are not recognized as a risk group category and they are not explicitly included in the objectives of mental health programs;
- habitually the cooperation between the somatic caring systems those focused on psychological and psychiatric help is non-structured, on a reciprocity bases, as liaison interdisciplinary examinations. Few medical somatic institutions have their own psychologist or psychiatrist. The greatest majority of the neurological and neurosurgery departments lacks of such professionals. A real interdisciplinary cooperation involves, as a starting point, common scientific research focused on the relationships between somatic and psychic disorders and finally the delivery of a new sort of service to the population;
- the preventive psychological intervention appears to be very useful for families with a severely acute central nervous system injury, but a number of subjective

and objective factors hinder the awareness of its value. Even more, the psychological support addressed to other persons than the ill patient, is regarded with ambivalence and fear. This offer has a hidden symbolic meaning that suggests the presence of an imminent additional danger, possible extended on the whole family, including the children. That is the reason why a large part of the community members, charged with old preconceived ideas, is not easy to convince about the opportunity of the preventive intervention, and some of them refuse with obstinacy;

- the professionals, neurologists and neurosurgeons, in Romania deprived in their early training of basic concepts of medical psychology about the needs for psychological support of chronically ill patients and their families, don't perceive the value of preventive psychological intervention and are difficult to persuade. Habitually, they preferred to exert an excessive protection of family vulnerability, keeping the reactions of healthy family members far of any approach, or to discuss them in a very simple manner;
- an efficient preventive psychological intervention service destined to children and their families having an acute CNS injured parent have to extend it's coverage area also to phases of illness after the patients' release from the hospital, by involving general practitioners.

4.3.2 Effects of the intervention

The psycho-traumatic events generated by acute central nervous system injury are lasting and complex, marked by crucial moments of evolution: the return of ill parents to their homes, the period of recovery and in some case the unhappy arrival of a stage of deficiency. Having this in mind, one could suppose that the return of an injured parent to his/her home could lead to an increase of children's and adolescents' level of psychological symptoms, due to a natural increase of exposure to the stressful stimuli generated by the illness.

Opposite to this expectation, the results showed a continuous decrease of total problems scales scores both from parental perspective and from self-report perspective, therefore this hypothesis was not supported by the current data. Several reasons can be given in this respect. First, the fact should not be neglected that the intervention group was analysed, which had received at least one counselling session until the intermediary evaluation, and therefore this could be an intervention effect. Second, in many cases, the ill parent, after returning home, requested to have separate counselling sessions with the therapist, expressing own concerns and problems. On the first place it was of course the child, his feelings and problems, but in fact, the emotional support was offered to the whole family. As a result, the children, in spite of being more exposed to the parental illness, also noticed that the emotional needs of the ill parent were taken care of professionally.

Regarding the question if a child-centered family counselling intervention especially designed for families with an acute central nervous system injured parent are more effective in reducing stress symptoms in children than an information brochure that gives guidance to parents and families how to address children’s needs in this situation, the data obtained in follow-up assessments (t2) from parental perspective, for the intervention group, shows a decrease in all second order scales scores of CBCL, even though the difference is not statistically significant. But, as it was mentioned before, all results were interpreted also from effect size perspective, and in this case, having an almost large effect size (d = 0.7) these results point out to a tendency according to which those receiving counselling have had a good evolution over time. Data from the control group showed that no amelioration of CBCL second order scales scores, emphasizing the fact the delivery of a brochure with basic information, even it is a real advance in helping families with an ill parent has limitations. The similarity in approach with direct counselling cannot reduce the fundamental limits of brochures imposed by the way of communication used. The written messages are directed almost only to the cognitive level. It lacks the emotional content, fundamental for supportive component of any counselling intervention, support needed also by the parent itself. Empowered by new information, the healthy parents remain the single real helpers who interpret new situations and acts in their own way. The number and variety of new situations and of possible life crises cannot be covered by limited dimensions and content of a brochure, often the parent being alone and helplessness.

In counselling intervention the direct interactions of therapist with the child and separate with the parents offer them the chance to be understood as distinct persons with own problems. From this perspective the preventive counselling intervention is different from classical family therapy (Minuchin, 1998) where the whole family is brought together for working through its conflicts. From the self-reporting perspective, the results showed a decrease of YRS second order scales scores over time for both experimental groups, with the remark that the difference is not statistically significant for the control group, but the effect size is a large one. These results, corroborated with parental perspective findings, support the idea that “face-to face” interventions through counselling sessions seems to be more effective in reducing children’s stress symptoms than written advices and recommendations by a brochure. In sum, the dialogic experience in counselling which involved emphatic listening and emotional support showed superior effect as merely psycho educative approach as administered by a brochure. The experimental controlled trial provided valuable data which suggest that for lasting and desirable outcomes truly dialogic intervention is necessary: a convenient duration, more sessions placed at reasonable intervals and acceptable settings, because the prevalent data showed that the therapeutic effects set up and grow up in time through a cumulative process.

4.3.3 Contentment of individuals with the intervention

In order to validate in a way the above findings the tests of therapeutic satisfaction were used, which confirmed the quality of intervention through high scores of success and acceptability reported from all participants’ perspectives (child, healthy parent and therapist).

One explanation of these good results could be found in the predominant medium and high level of education of parents from our sample. They have accepted the idea of preventive intervention and mediated the separate interviews with their children. The objectives of such type of intervention were reduction of intensity of the family emotional reactions, especially those of the children, a better understanding of ill parent reactions, a good involvement of each member of the family group into the process of care, of physical and psychological rehabilitation, the prevention of social isolation and the restarting of a normal life, as it is possible, in the same time with restoring of emotional rebalance.

The excellent degree of cooperation and compliance of family was expressed also through a minimal percentage of 3.4 % drop-outs compared with those habitually 30-40% met in psychotherapeutic practice (Haynal, Pasini & Archinard, 1997). The parents’ role was that of facilitators of therapeutic contacts with children. The preliminary discussions with them created a positive atmosphere for meetings with the children. The contacts with child include implicitly his healthy parent who is the majority of cases, the daily carrier of emotional support for children.

4.4 Limitations of the study

Despite a number of strengths of this study, it is not without its limitations. These limitations, do not affect its main findings, but bear on how they are interpreted. Taking into consideration that this study investigated a new field in child mental health (in Romania this was actually the first study on children of somatically ill parents), one could admit that a mere exploratory approach would suffice. For this dissertation, an important accent was put on hypothesis testing, which for some research questions was supplemented also by an exploratory analysis. Also, in several cases when the sample size was relatively limited, the decision was made to use both effect sizes and statistical significance in hypothesis testing. But, perhaps the most important limitation is the scarce of not having the same sample size for all analyses performed. Thus, as we mentioned before, regarding the Hy A1 and sub-hypothesis Hy A11, in 9 out of 16 cases of boys aged 11 – 18, and 13 out of 27 cases girls aged 11 – 18, data were only obtained from the self-reporting perspectives. This resulted in according missing in the parental reporting perspectives. As for the research question Q C2 and the corresponding hypothesis Hy C21, methodological issues placed serious difficulties in setting up a good analytic strategy. First, after the comparison of total problems score (both CBCL and YSR) between intervention and control groups it was found that their initial status were not as similar as it had been expected in a randomised distribution. Due to this artifact and also because the aim was to asses the time evolution only of those having problems, for measuring intervention effects, were included in analysis over time, only the cases which scored above the cut-off score, and therefore could be defined as symptomatic. The main assumption here was that for those not having problems it will be inappropriate to try to measure the intervention effect – one can ask the question – can they become more than normal? Here, one should be aware that this analytic strategy might cause some biases in the straight-forwardness of the work and therefore the results must be interpreted with caution. Moreover, one should be aware that no Romanian CBCL and YSR norms exist, and for current study German norms and clinical cut-off scores provided by Achenbach et al. (2001) were used as reference.

But, in order to be sure that the previous findings are not biased by the decision to include in the analysis only the symptomatic cases, the corresponding calculations were made for the entire sample and the corresponding results mirror almost entirely the previous findings and tendencies.

The inclusion criteria established in the project, which exclude the families with problems previous to current illness, or single parent families, divorced, not legally constituted, could be exactly the kind of family which, perhaps, are in more need of psychological support for their children than the families included in the research. Also the sample size could be considered a weak point, although there have been made a lot of efforts to overcome the recruitment obstacles presented before. Moreover, the recruitment and distribution of cases in experimental (intervention and control) groups, even if it was randomised, showed that their initial status were not as similar as it had been expected. As we have mentioned before, this is only an artifact, but one has to be aware of it.

The use of data from the other European partners involved in the project, although would have been desirable, unfortunately could not be done, primarily due to the fact that Romanian subproject was focused on a different type of disease, acute central nervous system injuries, and our partners were focused on chronic illnesses like cancer or multiple-sclerosis. Yet, some of the findings (example: affective responsiveness and affective involvement FAD subscales roles in children and adolescents psychological symptomatology) are mirrored both in German and UK data (Edwards et al., 2006; Romer et al., 2006), despite of differences in parental illnesses, which evidence the fact that, the life threat or absence of the ill parent, his suffering, depression and burden of healthy parent and need of reorganizing the roles in family, are effects encountered across different designs and samples.

4.5 Unresolved issues and implications for future research

The present study revealed that children of acute central nervous system injured parents showed increased levels of psychological symptomatology, sometimes three times higher than in a reference population. It will be extremely interesting for future studies to deep the analysis in this field, using larger samples and perhaps also different disease groups in order to identify also the disease role in children and adolescents outcome.

It was not one of the present study to analyse gender specific influence, but the observed higher risks for psychological problems in girls as compared to boys, requires further study on gender effects. Furthermore, the careful assessment of disease variables in patients and partners is needed to devise individualized intervention approaches to manage problems that might arise, for example, anxiety and depression. The importance of the partner’s mental health and emotional availability for the children has to be emphasized. Healthy parents need support in their parental role in order to decrease their concern with respect to their children (Harrison & Stuifbergen, 2002). Moreover, in order to go beyond the vague notion of “family empowerment” in family-based interventions, further analyses of differential aspects of family functioning are needed and therefore should be included in future research in the field of children of somatically ill parents.

Even though results of this the pilot intervention study are very preliminary and must be carefully looked at, they have revealed the tendency according to which the intervention group has had a good evolution over time. Moreover, it was also revealed that “face-to face” interventions through counselling sessions seemed to be more effective in reducing children’s stress symptoms than written advices and recommendations by a brochure. There is a clear need of further investigations, especially designed to avoid at least the methodological issues encountered in this present exploratory trial. Regarding the intervention process, there are still unanswered questions such as duration, timing, number of sessions, content and people involved, which are to be answered in future research.

4.6 Outlook: Implications for clinical practice

Regarding implications for clinical practice, one could extract some interesting ideas from the current study. First, it is obvious that using screening instruments such as CBCL and YSR, one could identify the families in need of psychological support. The results support the conclusion that in families with an ill parent, children are a risk category and this should not be overlooked in clinical work. Second, empirical data support the idea of interventions which try to strengthen families’ relational functioning in this particularly stressful life situation.

This attempt to identify the variables associated with children's and adolescents' psychological outcome has underlined the importance of some family related variables such as family functioning, clarity and acceptance of roles distribution, affective responsiveness, affective involvement and communication skills. One of the main implications of this study is that the mental health of adolescents is likely to be improved when their families are functioning well. Thus, interventions aimed at enhancing affective responsiveness, affective involvement and communication skills in the family could be helpful. Family members should also be encouraged to show an appropriate amount of interest in each other's activities, to be not too self-centred and to talk to each other about their problems and feelings.

The results suggest a number of interventions which may reduce the negative effects of parental acute central nervous system injury on a child. Specifically interventions aimed at helping parents to cope with the illness situation and to decrease individual parental depressive symptoms (Gonzalez, Steinglass & Reiss, 1989) may work to help children with their psychosocial outcome.

From empirical experience gained, the development of a preventive intervention program ought to follow some points such as:

- to be addressed both to child and his vulnerable depressed parent;
- to start with preferable separate, individual interviews with each member of family due to complexity of inner feelings, marked by magical thinking, projection and guilt;
- to be adjusted in content, timing and setting, according to specific client needs;
- external support should be provided at reasonable time interval of 1-2 month, for a period of at least 6 months, for obtaining the successful crossing of different stages of disease and of corresponding family reactions (Lazek, 1986);
- setting as main objectives the development of a better, realistic communication, of a mutual support between family members and a pro-active attitude toward life and its burden as challenges for survival.

Moreover, it should not be neglected the fact that in Romania there is not yet a real concern regarding early preventive psychological intervention for children and families with a parent having acute medium and/or severe central nervous system injury. Therefore, for implementation of those services, it is necessary to surpass a series of objective and subjective obstacles, as it was mentioned before. To ease the implementation process, as a first step, a large and persuasive activity of information, publication and dissemination at all levels of the COSIP study conclusions in the primary preventive psychological intervention field is necessary Then a long-term goal will be the setting up of psychological cabinets in all universitary neurology and neurosurgery clinics.

5 Summary

Although, it is well known that somatic illness in a parent is a risk factor for later psychiatric disorders in children (Rutter, 1966), the research on children of somatically ill parents is still rather scarce, and little attention has been paid to children's mental health when a parent is severely ill. In a review on parents with cancer, multiple sclerosis, heart disease or haemodialysis, Armistead, Klein & Forehand (1997) showed that children of seriously ill parents had higher scores in symptom scales than controls. Other reviews in this field (Worsham, Compas & Sydney, 1997) concluded also that parental illness generally caused moderate levels of distress in children. Yet, on an empiric level, acute illnesses have not been investigated thoroughly so far. In acute central nervous system injuries, the evolution of illness is different from other severe illnesses in parents, such as cancer, diabetes, multiple sclerosis, AIDS, haemophilia. And almost all publications on psychosocial aspects of acute central nervous system injuries were concerned with the sequelae of acute traumatic brain injury only on adult members of the family. Moreover, in Eastern European Countries like Romania there is not a constant professional awareness for needs of mental health prevention in children of somatically ill parents. Taking into consideration the above findings, it turned to be an important endeavour to investigate the mental health state of children having acute central nervous system injured parents and to elaborate on the specific needs for preventive counselling interventions in this field.

The aim of the present study was to evaluate and compare the data concerning types and frequencies of mental health problems in children of acute central nervous system injured parents, to specify interaction modalities of specific mental health risks and protective factors, to evaluate children's and parent's attitudes toward preventive interventions, as well as to evaluate an innovative family counselling intervention for families with an acute CNS injured parent and their children in an experimental controlled trial.

The data reported in this study were collected in the context of the Romanian COSIP Project which was part of the international research project COSIP – Children Of Somatically Ill Parent (QLG-4-CT-2001-02378, 5th Framework Program QoL) which was funded by the EU and coordinated by the Universitätsklinikum Hamburg-Eppendorf, Germany. During a 12-months period, all the cases hospitalised with specific pathology at neurosurgery clinic from "Dr. Bagdasar" Emergency Hospital were monitored. From those, all cases which fulfilled the inclusion criteria were selected. After consent was obtained the selected cases were included in the study and randomised between two experimental groups (control group/counselling group). Reporting perspectives of medical doctors, healthy parent and children were used in data collection. The instruments used aimed to measure patient's current physical state and performance (Karnofsky-Index), healthy parent physical and emotional health related quality of life (SF-8), degree of healthy parent depression (BDI), family functioning (FAD), documentation on sociodemographic and socio-economical status as well as health and other information related to the family environment of the child (BADO), emotional and behavioural problems in children and adolescents (CBCL, YSR), and opinion on intervention (FBB). As it was mentioned before, an important accent was put on hypothesis testing, which for some research questions was supplemented by an exploratory analysis. In statistical analysis, both effect sizes and statistical significance were used in hypothesis testing, especially when the sample size was relatively limited.

In order to answer the research question A (Which types and frequencies of mental health problems can be found in children of acute CNS injured parents?), the means of son and daughters of ill mothers and fathers were compared for externalizing and internalizing behaviours as well as for somatic complaints (both by parental reporting perspective – CBCL and by self-reporting perspective - YSR) with reference data, using both T tests for statistical significance and Cohen's “d” effect size. To answer research questions B1 (What are the specific mental health risk and protective factors for these children?) and B2 (Are children's problems rather related to the depression of the healthy parent or than to objective severity of the disease?), an explorative analysis was performed to determine which variables were predictors of YSR casesness. For examining the predictive power of the selected variables, such as illness severity, parents' objective physical impairment, parents' subjective well being, parental depression, family relational functioning for children's psychological outcome, Pearson correlations were calculated between any of the respective scores and the second order symptom scales of the YSR. Moreover, a set of multiple regression analyses was calculated to find out the set of associated factors which could best predict psychological problems in children and adolescents. For research questions C1 (Do children's detectable stress reactions as measured by psychological symptoms change over time after the traumatic event?) and C2 (Is a child-centered family counselling intervention especially designed for families with a CNS-injured parent more effective in reducing stress symptoms in children than an information brochure that gives guidance to parents and families how to address children's needs in this situation?), a comprehensive analysis was undertaken both for parental perspective (CBCL) and for self-report perspective (YSR). Therefore, evolution of second order (internalization, externalization and total problems) scales scores over time were compared within and between experimental groups.

Results showed that children of parents affected by central nervous system injury present significantly more mental health problems as compared to a reference population, both from healthy parent perspective and from self-reporting perspective. Moreover, prevalent data show a significant difference between internalization and externalization scales, pointing to the fact that mental health problems in adolescents are mainly reported within the internalizing spectrum. In addition, in a solely exploratory analysis, a comparison between boys and girls revealed a much higher rate of symptomatic individuals among girls, a tendency found both from parental perspective and self-reporting perspective. With regard to variables, which were associated with levels of psychological symptomatology in children and adolescents having a parent with acute CNS injury, objective disease characteristics seemed to have only little impact. However, the depression of the healthy parent comes along with high scores in children's mental health problems. Also, it was found that family dysfunction as a whole positively correlates with psychological symptoms in children and adolescents, and besides the general functioning subscale, mainly four sub dimensions of family functioning predicted children's problems, namely affective responsiveness, affective involvement, roles and communication. Results showed that the set of variables, which could best predict psychological problems of children and adolescents are healthy parent's health related quality of life (physical) (SF-8), healthy parent depression (BDI) and family dysfunction as a whole (FAD). However, a secondary regression analysis showed that healthy parent's health related quality of life (physical) - SF-8, together with healthy parent depression – BDI, and affective involvement subscale – FAD stands for 47% of the variance for children and adolescents in psychological symptoms, therefore, affective involvement FAD subscale seems to play a more specific role in children and adolescents psychological symptomatology than family general functioning. Furthermore, a tendency was revealed according to which those receiving counselling intervention have had a good evolution over time and that dialogic "face-to face" interventions through counselling sessions seemed to be more effective in reducing children's stress symptoms than psycho educative advices and recommendations by a written brochure. Those results were somehow confirmed by tests of therapeutic satisfaction through high scores of success and acceptability recorded by all participants (child, parent and therapist). Results were discussed in light of previously reported studies and also by reporting them to qualitative descriptions of practitioners and researchers.

Also, methodological limitations of the current study were considered, such as relatively limited sample size, the very narrow and strict inclusion criteria, and the encountered artifact regarding recruitment and distribution of cases in the two experimental groups. Moreover, a series of unresolved issues and ideas for future research were presented, as well as a brief outlook regarding implications for clinical practice and preventive interventions.

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7 List of tables

8 List of figures

9 Appendix

A The COSIP Study Group

B BADO Questionnaire

C The intervention concept and its setting

D Scientific standards of recruitment

E Schematized process of data management

F Descriptive elements of data screening and cleaning

G Scientific standards of data management

H Scientific standards of data analysis

I Control group brochure

Appendix A: The COSIP Study Group

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Appendix B: BADO Questionnaire

Basic Documentation (BADO-C)
Module for the ill parent's physician

COSIP
CHILDREN OF
SOMATICALLY
ILL PARENTS

____ ________________________
Surname, First Name (of ill parent) Date of Birth (DD/MM/YYYY)

____ ________________________
COSIP consultant COSIP-Center

____
Name of person documenting

COSIP-ID for ill parent:

______ ______ Country-Code	______ Sex	______ ______ Year of Birth	______ ______ ______ Family Number	______ Role in Family
AU =Austria CH =Switzerland DE =Germany DK =Denmark EL =Greece FN =Finland RO =Romania UK =United Kingdom	1 = ♂ 2 = ♀	►e.g. 1987 = 87	► Consecutive family ID-Number	Father = 1 Mother = 2 ► Count all children below the age of 18, who currently live in the household of one of the parents, then code: oldest child = 3 second oldest child = 4 etc.

If (1) is coded, please answer questions 2-7 only if these numbers are marked with an "a" in addition.
If (2) is coded, please answer questions 2-7 only if these numbers are marked with an "b" in addition.
If (3) is coded, please answer all of the following questions.
	01 Which parent is currently ill?
	Mother ....(1)
	Father ....(2)
	Both ....(3)

	Regarding the Illness of the mother:	**Regarding the Illness of the father:**
	02a What diagnoses according to ICD-10-No. were made? Please write full name(s) below: ______________________________ ______________________________ ICD-10-No.: ____________________	**02b What diagnoses according to ICD-10-No. were made?** Please write full name(s) below: ______________________________ ______________________________ ICD-10-No.: ____________________
	03a When was the leading diagnosis made? Month/Year:____ ____ / ____ ____ unknown .... (88/88)	**03b When was the leading diagnosis made?** Month/Year:____ ____ / ____ ____ unknown .... (88/88)
	04a Onset of illness acute .... (1) subacute .... (2) lingering .... (3)	**04b Onset of illness** acute .... (1) subacute .... (2) lingering .... (3)
► "genetic" = genetic defect is identified (e.g. haemophilia, Chorea Huntington)	**05a Aetiology of illness** genetic .... (1) multifactorial (including genetic risk) .... (2) infectious .... (3) accident .... (4) other illness (please specify below): .... (5) ______________________________ unknown (6)	**05b Aetiology of illness** genetic .... (1) multifactorial (including genetic risk) .... (2) infectious .... (3) accident .... (4) other illness (please specify below): .... (5) ______________________________ unknown (6)
►refers to the last year ► "progressive" = worsening of health state or impairment within the last 12 months ► „static" = state of impairment remains stable over a period of one year or more	**06a Course of Illness in the past** static .... (1) relapse of illness in the last year after complete remission............ (2) progressive .... (3) improvement (but no remission)..... (4)	**06b Course of Illness in the past** static .... (1) relapse of illness in the last year after complete remission............ (2) progressive .... (3) improvement (but no remission)..... (4)

► “cured” = stabile and complete remission (no cancer cells in the last 5 years) ► “stable” = impaired status can be expected over the next 12 months (e.g. neurological residual symptoms after accident; patient stable under dialysis) ► “progressing” = e.g. multiple sclerosis ► “terminal” = all medical measures are palliative ►in cases of doubt, please code “insecure”	**07a Prognosis** cured ....(1) stable ....(2) progressing ....(3) insecure ....(4) terminal ....(5)	**07b Prognosis** cured ....(1) stable ....(2) progressing ....(3) insecure ....(4) terminal ....(5)

Basic Documentation (BADO-C)
Module for mothers on herself

COSIP
CHILDREN OF
SOMATICALLY
ILL PARENTS

____
Name of mother documenting

COSIP-ID of mother:

_____ _____ Country-Code	_____ Sex	_____ _____ Year of Birth	_____ _____ _____ Family Number	_____ Role in Family
AU =Austria CH =Switzerland DE =Germany DK =Denmark EL =Greece FN =Finland RO =Romania UK =United Kingdom	1 = ♂ 2 = ♀	►e.g. 1987 = 87	► Consecutive family ID-Number	Father = 1 Mother = 2 ► Count all children below the age of 18, who currently live in the household of one of the parents, then code: oldest child = 3 second oldest child = 4 etc.

► Refers to the sociological mother, that is the person, who takes over the major role as „mother" for the child	**01 Mother's year of birth** ___ ___ ___ ___ unknown .... (8888)
► Each partner nation may pick its favourite answers and arrange codes according to their needs. ► Refers to the sociological mother, that is the person, who takes over the major role as „mother" for the child	**02 Education level of <u>mother</u>/guardian** no school level completed .... (98) GER .... (101-200) AU .... (201-300) DK .... (301-400) FIN .... (401-500) HEL .... (501-600) ROM .... (601-700) CH .... (701-800) UK .... (801-900) unknown .... (901)
► Refers to the sociological mother, that is the person, who takes over the major role as „mother" for the child ► „Homecare" refers to doing the household/ homemaking	**03 Work situation of <u>mother</u>/guardian** full time employment .... (1) shift work (no part-time employment) .... (2) regular part-time employment .... (3) self employed/informal work .... (4) unemployed .... (5) unemployed/in training, retraining .... (6) unemployed/retired .... (7) works in household .... (8) unknown .... (9)

► Originally this question refers to the person with the highest status in the core family. For the German team we decided to turn this question into the following to open questions and ask both parents: 04: In which profession do you currently work, or which profession have you learned? 05: In which position do you currently work? We ask this question both parents, as we don’t know yet, which parent ranks higher. After we have made up our mind for good category definitions, we recode the answers given. We strongly recommend to do this as well. ► Refers to sociological parents.	**04/05 Socio-economic status** does not apply (98) *If employed:* unskilled worker (1) semi-skilled worker, apprentice (2) skilled worker, craftsman, clerk, lower-grade civil servant (3) higher-grade employee, higher-grade civil servant (4) senior-grade employee, clerical-grade civil servant (5) executive employee, senior-grade civil servant (6) *If self-employed:* smallest independent worker, informal sector (7) small sole independent business (8) independent craftsman, farmer, manager of small-scale business (9) independent craftsman, farmer etc. (middle-scale business) (10) academic, consultant, entrepreneur (11) unknown (12)

Basic Documentation (BADO-C)

Module of Fathers on himself

____
Name of father documenting

COSIP-ID of father:

_____ _____ Country-Code	_____ Sex	_____ _____ Year of Birth	_____ _____ _____ Family Number	_____ Role in Family
AU =Austria CH =Switzerland DE =Germany DK =Denmark EL =Greece FN =Finland RO =Romania UK =United Kingdom	1 = ♂ 2 = ♀	►e.g. 1987 = 87	► Consecutive family ID-Number	Father = 1 Mother = 2 ► Count all children below the age of 18, who currently live in the household of one of the parents, then code: oldest child = 3 second oldest child = 4 etc.

► Refers to the sociological father, that is the person, who takes over the major role as „father" for the child	**01 Father's year of birth** ___ ___ ___ ___ unknown ....(8888)
► Each partner nation may pick its favourite answers and arrange codes according to their needs. ► Refers to the sociological father, that is the person, who takes over the major role as „father" for the child	**02 Education level of <u>father</u>/guardian** no school level completed ....(98) GER ....(101-200) AU ....(201-300) DK ....(301-400) FIN ....(401-500) HEL ....(501-600) ROM ....(601-700) CH ....(701-800) UK ....(801-900) unknown ....(901)
► Refers to the sociological father, that is the person, who takes over the major role as „father" for the child ► „Homecare" refers to doing the household/ homemaking	**03 Work situation of <u>father</u>/guardian** full time employment ....(1) shift work (no part-time employment) ....(2) regular part-time employment ....(3) self employed/informal work ....(4) unemployed ....(5) unemployed/in training, retraining ....(6) unemployed/retired ....(7) works in household ....(8) unknown ....(9)

► Originally this question refers to the person with the highest status in the core family. For the German team we decided to turn this question into the following to open questions and ask both parents: 04: In which profession do you currently work, or which profession have you learned? 05: In which position do you currently work? We ask this question both parents, as we don’t know yet, which parent ranks higher. After we have made up our mind for good category definitions, we recode the answers given. We strongly recommend to do this as well. ► Refers to sociological parents.	**04/05 Socio-economic status** does not apply (98) *If employed:* unskilled worker (1) semi-skilled worker, apprentice (2) skilled worker, craftsman, clerk, lower-grade civil servant (3) higher-grade employee, higher-grade civil servant (4) senior-grade employee, clerical-grade civil servant (5) executive employee, senior-grade civil servant (6) *If self-employed:* smallest independent worker, informal sector (7) small sole independent business (8) independent craftsman, farmer, manager of small-scale business (9) independent craftsman, farmer etc. (middle-scale business) (10) academic, consultant, entrepreneur (11) unknown (12)

Basic Documentation (BADO-C)
Module for mothers on each child

COSIP CHILDREN OF SOMATICALLY ILL PARENTS

_______________________________________ Surname, First Name of child, questions refer to

_______________________ Child's Date of Birth (DD/MM/YYYY)

_______________________________________ Name of mother filling out the questionnaire

COSIP-ID of respective child:

______ ______ Country-Code	______ Sex	______ ______ Year of Birth	______ ______ ______ Family Number	______ Role in Family
AU =Austria CH =Switzerland DE =Germany DK =Denmark EL =Greece FN =Finland RO =Romania UK =United Kingdom	1 = ♂ 2 = ♀	►e.g. 1987 = 87	► Consecutive family ID-Number	Father = 1 Mother = 2 ► Count all children below the age of 18, who currently live in the household of one of the parents, then code: oldest child = 3 second oldest child = 4 etc.

General information on the child

	01 Name of the child ____
	02 Birth date of the child ___ ___ . ___ ___ . ___ ___ ___ ___
► If no siblings there, code „00“.	**03 Number of Biological siblings** ____ ____ unknown ....(88)
► Biological Sex of child	**04 Sex of child** male ....(1) female ....(2)
► Each partner nation may pick its favourite answers and code it after numerical ISO ALPHA 3 codes. Remember to put a “other (please specify)” category into your questionnaire, if you rearrange this question.	**05 Nationality of child** German ....(276) Austrian ....(040) Danish ....(208) Finnish ....(246) Greek ....(300) Romanian ....(642) Swiss ....(756)

	Member of the United Kingdom ....(826) Other (please specify): ....(xxx) ______________________________
► If both parents are ill, please mark two answers in question 8a.. If only one parent is ill, then please tick only one answer in question 8a and one answer in question 8b.	**06 The ill parent is the child's…** biological father ....(1) biological mother ....(2) step father ....(3) step mother ....(4) adoptive father ....(5) adoptive mother ....(6) foster father ....(7) foster mother ....(8) other mother (please specify): ....(9) ______________________________ other father (please specify): ....(10) ______________________________
► The word "parent" here refers to the person, who takes over a major part of the parental role.	**07 The healthy parent or other person, who takes over a major part of the parental role, is the child's…** Does not apply, there is no such person..........(98) biological father ....(1) biological mother ....(2) step father ....(3) step mother ....(4) adoptive father ....(5) adoptive mother ....(6) foster father ....(7) foster mother ....(8) other mother (please specify): ....(9) ______________________________ other father (please specify): ....(10) ______________________________
►Refers to the child.	**08 Previous consultations for psychological problems** none ....(1) psychological counselling ....(2) out-patient psychiatric treatment ....(3) in-patient psychiatric treatment ....(4) out- and in-patient psychiatric treatment ....(5) treatment not otherwise specified ....(6) other (please specify): ______________________________(7) unknown ....(8)

Living Arrangements

► A new partner of the father, even if both aren’t married (yet) but live together in the same household, is coded as stepmother.	**09 Child lives with Mother/Guardian:** biological mother .... (1) stepmother .... (2) adoptive mother .... (3) foster-mother .... (4) grandmother .... (5) relatives, or mother substitute .... (6) no mother .... (7) unknown .... (8)
► A new partner of the mother, even if both aren’t married (yet) but live together in the same household, is coded as stepfather.	**10 Child lives with Father/Guardian:** biological father .... (1) stepfather .... (2) adoptive father .... (3) foster-father .... (4) grandfather .... (5) relatives, or father substitute .... (6) no father .... (7) unknown .... (8)
	11 Other living conditions not mentioned in items 9/10
	Caution: If child lives an above mentioned person (9/10), then tick here and go to question 12. *does not apply .... (98)*
► Does a child live „normally“ with its parents, then code „does not apply“ ► If a child lives in boarding school, then code questions 13 and 14 according to the situation at home (e.g. on weekends) and code question 15 as „does not apply“.	adolescent residential care .... (1) rehab-/therapy centre .... (2) lives alone .... (3) married or lives with partner/commune .... (4) emergency shelter (e.g. shelter for abused women) .... (5) homeless .... (6) unknown .... (7)

Biological Parents

► please give only one answer	**12 Are biological parents still alive?** both alive .... (1) father dead .... (2) unknown if father is alive .... (3) mother dead .... (4) unknown if mother is alive .... (5) both dead .... (6) unknown regarding both parents .... (7)
	Caution: If no biological parent dead, please tick here and go to question 17. **Does not apply, no biological parent dead .... (98)**
	13 Cause of mother’s death does not apply (mother alive) .... (98) illness .... (1) accident .... (2) suicide .... (3) homicide .... (4) other (please specify below, if possible) .... (5) ____

14 Year of mother’s death

___ ___ ___ ___

unknown .... (8888)

15 Cause of father’s death

does not apply (father alive) .... (98)
illness .... (1)
accident .... (2)
suicide .... (3)
homicide .... (4)
other (please specify below, if possible): .... (5)

16 Year of father’s death

___ ___ ___ ___

unknown .... (8888)

History including family history

17 Age of mother at childbirth (years)

___ ___

unknown .... (88)

18 Complications/risk factors

	No	Yes	unknown
18a During pregnancy	(1)	(2)	(3)

► If yes, please specify below:

	No	Yes	unknown
18b During labour and delivery	(1)	(2)	(3)

► If yes, please specify below:

	No	Yes	unknown
18c Postpartum	(1)	(2)	(3)

► If yes, please specify below:

18d Has there been at least one constant contact person, which cared for the child on a regular basis throughout the first three years?

	No	Yes	unknown
Constant contact person	(1)	(2)	(3)

19 Child developmental disorders

Has the child received treatment for one or more of the following disorders?

	No	Yes	unknown

19a Motor	(1)	(2)	(3)

► If yes, please specify below:

____

	No	Yes	unknown
19b Speech	(1)	(2)	(3)

► If yes, please specify below:

____

	No	Yes	unknown
19c Cleanliness	(1)	(2)	(3)

► If yes, please specify below:

____

► By „serious illness“incidences are meant, which
- (a) required at least two hospitalizations of longer than 1 week duration of the child or
- (b) states, that require medical supervision on a regular basis.

	No	Yes	unknown
20 Serious illness during childhood	(1)	(2)	(3)

► If yes, please specify below:

____

21 Life Events

Have these incidences taken place in the child's life referring to the last 6 months?

21a Mental disorder, deviance or handicap in child's primary support group

	No	Yes	unknown
parental mental disorder/deviance	(1)	(2)	(3)
disability in sibling	(1)	(2)	(3)
other (please specify):_________________	(1)	(2)	(3)

21b Acute life events

	No	Yes	unknown
loss of a love relationship	(1)	(2)	(3)
events resulting in loss of self-esteem	(1)	(2)	(3)
sexual abuse (extrafamilial)	(1)	(2)	(3)
personal frightening experience	(1)	(2)	(3)
other (please specify):_________________	(1)	(2)	(3)

21c Societal stressors

	No	Yes	unknown
persecution or adverse discrimination	(1)	(2)	(3)
migration or social transplantation	(1)	(2)	(3)
other (please specify):_________________	(1)	(2)	(3)

21d Chronic stressors associated with school/work

	No	Yes	unknown
discordant relationships with peers	(1)	(2)	(3)
scapegoating of child by teachers or work supervisors	(1)	(2)	(3)
unrest in school/work situation	(1)	(2)	(3)
other (please specify):_________________	(1)	(2)	(3)

► If child is a boy, then code (98) here.

22a Menses

Caution: For girls only! If child is a boy, please tick here and go to question 22b!

Does not apply (boy) .... (98)

Not Yet .... (1)

Yes .... (2)

► If yes, age at menarche: ___ ___ unknown .... (88)

Unknown .... (3)

► If child is a girl, then code (98) here.

22b Start of change of voice (deepening)

Caution: For boys only! If child is a girl, please tick here and go to question 23!

Does not apply (girl) .... (98)

Not Yet .... (1)

Yes .... (2)

► If yes, age at start of change of voice: ___ ___ unknown (88)

Unknown .... (3)

Questions regarding Kindergarten

24 Kindergarten/Day Nursery

► If „does not apply, child too young“, then go to question 35.

Caution: If child too young for kindergarten/day nursery, please tick here and go to question 35!

Does not apply, child too young for Kindergarten/day nursery .... (98)

► If child is not currently enrolled in establishment (e.g. child is too old and attends school already), then code “none”.

Social/educational establishment, where child is enrolled:

None .... (10)
GER .... (11-20)
AU .... (21-30)
DK .... (31-40)
FIN .... (41-50)
HEL .... (51-60)
ROM .... (61-70)
CH .... (71-80)
UK .... (81-90)
unknown .... (91)

► Should also be asked retrospectively.

25 Disorders while attending Kindergarten/ Day Nursery (including history)

	not applicable	no	yes	unknown
separation anxiety	(98)	(1)	(2)	(3)
contact disorder	(98)	(1)	(2)	(3)
developmental play difficulties	(98)	(1)	(2)	(3)
hyperactive behaviour	(98)	(1)	(2)	(3)
poor conduct / aggression	(98)	(1)	(2)	(3)
other (please specify below):	(98)	(1)	(2)	(3)

____

Questions regarding School

► Should be answered for everybody (also retrospecitvely)	**26 Started School** does not apply, child too young for attending school (98) on time (1) premature (2) postponed (3) unknown (4)
	27 School History does not apply, child too young for attending school (98) regular (1) repeated once (2) repeated several times (3) school transfer (4) repetition and transfer (5)
	28 Did the child leave school prematurely? does not apply (e.g. child hasn't attended school yet) (98) No (1) Yes, left school by own decision (2) Yes, school career ended by school authority (3) Yes, for other reasons (please specify): ______________________________ (4) unknown (5)
► Should be answered for everybody (also retrospecitvely)	**29 School disorders** Have you or the children's school initiated to seek professional help for any of the following problems? does not apply, child too young for attending school (98) no yes unknown poor conduct/aggression (1) (2) (3) school achievement difficulties (1) (2) (3) social problems (1) (2) (3) concentration difficulties (1) (2) (3) hyperactive behaviour (1) (2) (3) truancy (1) (2) (3) school refusal/school phobia (1) (2) (3) other (please specify below): (1) (2) (3) ______________________________
► Each partner nation may pick its favourite answers and arrange codes according to their needs. ► „not applicable" means,child hasn't had the chance yet to complete a school level. ► „none completed" means child has had the chance to complete a school level, but didn't succeed in doing so.	**30 School level completed** not applicable (98) no school level completed (100) GER (101-200) AU (201-300) DK (301-400) FIN (401-500) HEL (501-600) ROM (601-700) CH (701-800) UK (801-900) unknown (901)
	31 Current employment situation of adolescent

	not yet qualified for employment/incapacity ....(1) unemployed ....(2) in police custody ....(3) protected work environment..........(4) vocational training/employed as (please specify below):..........(5) ______________________________ occasional work (e.g. summer jobs)..........(6) unknown ....(7)
► If “Does not apply…”, then go to question 35!	*Caution: If child not currently enrolled in school, please tick here and go to question 35!* *Does not apply, child not enrolled in school ....(98)*
	32 Present class (or equivalent) If child in school, please indicate class below: ___ ___ unknown ....(88)

► Refers to the last school report!	**33 Academic performance** Last grades in… …mother tongue:____ …mathematics : ____
► Each partner nation may pick its favourite answers and arrange codes according to their needs.	**34 School at which child is currently enrolled** GER ....(101-200) AU ....(201-300) DK ....(301-400) FIN ....(401-500) HEL ....(501-600) ROM ....(601-700) CH ....(701-800) UK ....(801-900) unknown ....(901)

Home and Family

	35 Twin or Triplet etc.? No ....(1) Yes ....(2) Unknown ....(3)
► Question wants to evaluate how many other children (that is persons younger than 18 years of age) are living with the child in its family.	**36 Number of children in family with whom child resides** ____ ____ unknown ....(88)
►Count all biological siblings (even, if they have moved out already) and all sociological siblings, with whom the child lives together.	**37 Birth order of child in family** only child ....(1) youngest child ....(2) middle child ....(3) oldest child ....(4) unknown ....(5)

Momentary Health Status

	38 Does the child need medical treatment or monitoring for any bodily disease (e.g. asthma) on a regular basis? No (1) Yes (2) ► If yes, which disease(es)? (please specify below): Unknown (3)

	39 Does the child take any medicine for a bodily disease on a regular basis? No (1) Yes (2) ► If yes, which medicine? (please specify below): medicine: Unknown (3)	
	Regarding the Illness of the father:	**Regarding the Illness of the mother:**
	If the father is not ill, then tick here. You have finished the questionnaire then. Thank you. *father not ill (98)*	*If the mother is not ill, then tick here. You have finished the questionnaire then. Thank you.* *mother not ill (98)*
	40 Since the diagnosis was made, have there been any changes in condition or behaviour? No (1) Yes (2) ► If yes, please specify below what kind of changes? Unknown (3)	**41 Since the diagnosis was made, have there been any changes in condition or behaviour?** No (1) Yes (2) ► If yes, please specify below what kind of changes? Unknown (3)

Basic Documentation (BADO-C)

Module for mothers on the family

COSIP
CHILDREN OF
SOMATICALLY
ILL PARENTS

____
Name of mother documenting

COSIP-ID of mother:

Country-Code	Sex	Year of Birth	Family Number	Role in Family
_____ _____	_____	_____ _____	_____ _____ _____	_____
AU =Austria CH =Switzerland DE =Germany DK =Denmark EL =Greece FN =Finland RO =Romania UK =United Kingdom	1 = ♂ 2 = ♀	►e.g. 1987 = 87	► Consecutive family ID-Number	Father = 1 Mother = 2 ► Count all children below the age of 18, who currently live in the household of one of the parents, then code: oldest child = 3 second oldest child = 4 etc.

		01 Which parent is currently ill? Mother .... (1) Father .... (2) Both .... (3)
	If only the mother is ill in the family, please code all questions in the left column (marked with "a"). If only the father is ill in the family, please code all questions in the right column (marked with "b"). If both parents are ill, please code questions in both columns.	
	Regarding the Illness of the mother:	**Regarding the Illness of the father:**
	2a What diagnoses were made? Please write full name(s) below: ____________________________ ____________________________ ____________________________	**2b What diagnoses were made?** Please write full name(s) below: ____________________________ ____________________________ ____________________________
	3a When was the leading diagnosis made? Month/Year:____ ____ / ____ ____ unknown .... (88/88)	**3b When was the leading diagnosis made?** Month/Year:____ ____ / ____ ____ unknown .... (88/88)
	4a Have there been any hospitalisations? No (1) Yes (2)	**4b Have there been any hospitalisations?** No (1) Yes (2)

	Caution: If there were no hospitaliations, please tick here and go to question 70. *Does not apply, no hospitalisations..(98)*	*Caution: If there were no hospitaliations, please tick here and go to question 70.* *Does not apply, no hospitalisations..(98)*
	5a How many hospitalisations were there? 1 (1) 2-4 (2) 5 or more (3)	**5a How many hospitalisations were there?** 1 (1) 2-4 (2) 5 or more (3)
► code May 2001 as "05/01"	**6a When was the first hospitalisation?** Month/Year:____ ____ / ____ ____ unknown (88/88)	**6b When was the first hospitalisation?** Month/Year:____ ____ / ____ ____ unknown (88/88)
	7a Who looked after the child in that time? Please specify below (e.g. grandmother, neighbour): ________________________________	**7b Who looked after the child in that time?** Please specify below (e.g. grandmother, neighbour): ________________________________

Basic Documentation (BADO-C)

Module for counsellors on each child

COSIP CHILDREN OF SOMATICALLY ILL PARENTS

______________________________________ Surname, First Name of child, questions refer to

______________________ Child's Date of Birth (DD/MM/YYYY)

______________________________________ Name of counsellor documenting

COSIP-ID for respective child:

_____ _____ Country-Code	_____ Sex	_____ _____ Year of Birth	_____ _____ _____ Family Number	_____ Role in Family
AU =Austria CH =Switzerland DE =Germany DK =Denmark EL =Greece FN =Finland RO =Romania UK =United Kingdom	1 = ♂ 2 = ♀	►e.g. 1987 = 87	► Consecutive family ID-Number	Father = 1 Mother = 2 ► Count all children below the age of 18, who currently live in the household of one of the parents, then code: oldest child = 3 second oldest child = 4 etc.

► Item should evaluate the mode of the first contact with COSIP ► Only one answer possible	**11 Context of first contact with COSIP** out-patient consultation .... (1) consultation in the context of parent's in-patient hospitalization .... (2) other (please specify): ________ (3)
► Item should evaluate, which person initiated first contact with COSIP ► „either parent" includes biological as well as social parents ► If contact evolved through a medical consultation, please code fort he person, who initiated the consultation.	**12 Person, who made first contact with COSIP** either parent .... (1) child .... (2) other family member .... (3) ill parent's physician .... (4) ill parent's psychotherapist .... (5) primary research context .... (6) other (please specify): ________ (7)
	03 Was there a personal face-to-face contact between you and a family-member? No .... (1) Yes .... (2)
	If there was no personal face-to-face contact between you and a family member, then tick here please. You have ended the questionnaire then.

	Face-to-face contact didn't exist (98)

► Date of first face-to-face contact with either member of the family ► code e.g. 24th February 2003 as 24.02.2003	**13 Date of beginning of consultation** ___ ___ . ___ ___ . ___ ___ ___ ___
► Refers to the sociological mother ► Code "unknown" here, if you haven't seen the mother personally.	**71 Does the mother show any psychic abnormalities?** does not apply (98) No (1) Yes (2) ► If yes, please specify psychic abnormalities below: ____ Unknown (3)
►Refers to the sociological father. ► Code "unknown" here, if you haven't seen the father personally.	**72 Does the father show any psychic abnormalities?** does not apply (98) No (1) Yes (2) ► If yes, please specify psychic abnormalities below: ____ Unknown (3)
	55 Assessment of Co-operation of… not applicable / good / fair / poor / bad parents/guardians (98) (1) (2) (3) (4) child (98) (1) (2) (3) (4)
	54 Type of Finishing regular (1) premature termination by patient/parents (2) premature termination by therapist (3)
► Last face-to-face contact with any family member ► code e.g. 24th February 2003 as 24.02.2003	**53 Date of end of Consultation** ____ ____ . ____ ____ . ____ ____ ____ ____
	In the following section, you'll find some questions regarding your client __(name of child)__. Please answer the following questions only referring to this child.
	03 Was there a personal face-to-face contact between you and this child? No (1) Yes (2)
	If there was no personal face-to-face contact between you and this child, then tick here please. You have ended the questionnaire then. *Face-to-face contact didn't exist (98)*
	31 Life Events Have these incidences taken place in the child's life referring to the last 6 months? No / Yes / unknown **a. Abnormal intrafamilial relationships** lack of warmth in parent-child relationship (1) (2) (3) intrafamilial discord among adults (1) (2) (3) hostility towards or scapegoating of the child (1) (2) (3) physical child abuse (1) (2) (3) sexual abuse (within the family) (1) (2) (3)

other (please specify):__________________	(1)	(2)	(3)

b. Inadequate/distorted intrafamilial communication	(1)	(2)	(3)

c. Abnormal qualities of upbringing

parental overprotection	(1)	(2)	(3)
inadequate parental supervision/control	(1)	(2)	(3)
experiential privation	(1)	(2)	(3)
inappropriate parental pressure	(1)	(2)	(3)
other (please specify):__________________	(1)	(2)	(3)

d. Abnormal immediate environment

institutional upbringing	(1)	(2)	(3)
anomalous parenting situation	(1)	(2)	(3)
isolated family	(1)	(2)	(3)
living conditions that create a potentially hazardous psychosocial situation	(1)	(2)	(3)
other (please specify):__________________	(1)	(2)	(3)

e. Acute life events

removals from home carrying significant contextual threat	(1)	(2)	(3)
negatively altered pattern of family relationship	(1)	(2)	(3)
other (please specify):__________________	(1)	(2)	(3)

► code only after face-to-face-contact

57 Indications for a psychotherapeutic treatment of the child

	none	little	middle	considerable	strong
urgency of therapy for child	(1)	(2)	(3)	(4)	(5)
child's capacity	(1)	(2)	(3)	(4)	(5)
child's motivation	(1)	(2)	(3)	(4)	(5)

58 Recommended Placement outside the home

(1)= none
(2)= is indicated/recommended
(3)= ordered/initiated

nursery	(1)	(2)	(3)
home/supervised commune	(1)	(2)	(3)
residential care facility	(1)	(2)	(3)
boarding school	(1)	(2)	(3)
foster home/adoption	(1)	(2)	(3)

03 Has the child received any further treatment within COSIP?

No	(1)
Yes	(2)

If the child didn't receive any further treatment, then tick here please. You have ended the questionnaire then.

Further treatment didn't exist	*(98)*

51 Duration of treatment/counselling for child

number of sessions	none	1-5	6-10	11-25	26-50	>50
child/adolescent						

counselling/treatment	(1)	(2)	(3)	(4)	(5)	(6)
child/adolescent counselling/treatment including caregiver	(1)	(2)	(3)	(4)	(5)	(6)
psychodynamic psychotherapy	(1)	(2)	(3)	(4)	(5)	(6)
behaviour therapy	(1)	(2)	(3)	(4)	(5)	(6)
play therapy	(1)	(2)	(3)	(4)	(5)	(6)
role play, group therapy	(1)	(2)	(3)	(4)	(5)	(6)
other psychotherapeutic modalities	(1)	(2)	(3)	(4)	(5)	(6)

52 Social Interventions

	No	Yes
Consultations to kindergarten/schools	(1)	(2)
Consultation to institutions	(1)	(2)
Consultation to social services/youth welfare department	(1)	(2)
Case conferences or support groups	(1)	(2)
Consultation with other therapist	(1)	(2)
House calls/home treatment	(1)	(2)

03Was a further psychotherapeutic intervention for the child recommended?

No (1)
Yes (2)

If a further psychotherapeutic intervention for the child was not recommended, then tick here please. You have ended the questionnaire then.

Further treatment not recommended (98)

56 Recommended further treatment/counselling

►Continuing sporadic/low frequency counselling (no specific treatment)	(1)	(2)	(3)
► out-patient therapy modalities			
family therapy	(1)	(2)	(3)
psychodynamic therapy	(1)	(2)	(3)
behaviour therapy	(1)	(2)	(3)
play therapy	(1)	(2)	(3)
occupational therapy	(1)	(2)	(3)
group therapy	(1)	(2)	(3)
individual psychotherapy of parent	(1)	(2)	(3)
couple therapy/marital counselling for parents	(1)	(2)	(3)
► Child and adolescent psychiatric or psychotherapeutic treatment			
out-patient	(1)	(2)	(3)
day-clinic	(1)	(2)	(3)
in-patient	(1)	(2)	(3)

Appendix C: The intervention concept and its setting

The conceptual frame for counseling of parents and children was based on humanistic theory (Rogers, 1987; Egan, 1990; Nelson-Jones, 1991), preventive psychiatry, psychotraumatology (Riedesser & Fisher, 2001), crisis intervention concepts, principles of family therapy, the individual brief therapy for children (Mattejat, 1997; Graham, Turk & Verhulst, 1999). From the various types of psychotherapeutically interventions, it was selected the problem-centered, brief intervention model most suited for a needy family with low time availabilities.

One of the main points of therapeutic intervention is the development of therapeutic relationship (Oancea, 2002). The establishment of a therapeutic alliance meets substantial difficulties mainly due to low clients' motivation, the overt intent of therapist to influence too much the client, the use of "anticipatory guidance" which can frighten with premature communication of bad news. It seems that a good beginning, the first contact with healthy parent is decisive for agreement of refusal. The ingredients of success include more elements as the atmosphere, strong influenced by friendly attitude of the therapist, full understanding in moments of relational tension. In introductory remarks the therapist introduces himself as professional, presents the project of intervention, the offer of help and its preventive qualities, its limits and stimulates the discussions about the content, the questioning from the parent. The parents and their needs for emotional protection of the child, their feelings about what is good for the child will be a heavy decisional factor in selection of offered information. If the parent agrees it follows immediately preliminary arrangements with obtaining of the written parental consent which is a guarantee for the achievement of a systematic process. All parents who signed the consent got over the whole process of counseling. Preliminary arrangements include also settings (in practice most preferred were home visits), means of communications, and settlement of regular contacts with flexible schedules depending on clients' availability.

The content of intervention presented by Russ (1998) is completed with statements suited for such type of counseling:

- empathic listening starting with cognitive mapping and active emotional support for family and child;
- catharsis and labeling of negative feelings. That means identification and development of “normalization” process of:
    - distress and pain about the negative event;
    - frustration and anger against destiny, or someone which is guilty, discussing possible magical infantile guilt related to parental illness;
    - confusion about future of ill person and of rest of the family.
- corrective emotional experience by introducing of hope and security by emotional support and an active problem solving perspective;
- offering information/ making sense of what is happened and what is expected to happen, but only at the clients demand;
- developing insight and working through / clarifying questions about previous parental attitudes toward the children, the suggested realistic communication style, promotion of more intimate relationships, recognition of reciprocal needs for support between parents and their child;
- learning the alternative ways of problem solving and by defining the burden on himself and the family, establishing the dimensions of tasks, identifying the resources inclusive that of children, establishing together the differentiated family tasks. It is important to know that children cannot offer a constant long-term active help to their family mainly due to their dominant needs for play and active life (Barry, n.d.);
    - development of a new sense of life, with sacrifices and the satisfaction of offering help;
    - assesing the difficulties in attainment of proposed objectives. As usually each session will start with the evaluation the period between meetings, recording the achievements, the difficulties, discussions the about the ways to solve them.

Appendix D: Scientific standards of recruitment

All procedures of data collection have been harmonized among transnational partners to a possible degree, so that data are gained on the same basis, which is a prerequisite for making data comparable. Careful attention was given to sampling. As we want to gain knowledge about both children of somatically ill parents and their situation in general and knowledge about counselling services for children of somatically ill parents we have to differentiate between the population of children of somatically ill parents as a whole, and children of somatically ill parents who want to take advantage of counselling services. Therefore we have to be aware of selection issues when drawing together participating subjects, as it will make a difference to our sampling, whether only persons are included in the study who want to take advantage of our counselling service, or whether we also include subjects who don’t get counselling. Wherever data are collected, this issue of selection effects has to be adequately considered and ways of selection of subjects to our study group have to be described with great care. Moreover, strong effort should be made in order to get as many information as possible about families who don’t want to participate in the study and/or take advantage of the counselling service.

The following three levels of possible selective effects have to be distinguished:

- Institutional selection effects: To which degree does the medical institution in which ill parents are recruited select patients from the overall patient population in a disease group (make reference to your context analysis)?
- Selection effects due to parent participation in the study: To which degree are parent subjects participating in the study selectively different from those not participating for whatever reasons?
- Selective effects due to different child mental health states: To which degree are children participating in the study selectively distinguishable from those not participating concerning their mental health state and/or sociodemographic variables?

Moreover, times of measurement must be carefully selected. It should be clear that the first time of measurement (t_0) for the cross-sectional analysis of mental health status and associated risk factors takes place before any kind of explicit intervention has started. Other points of measurement are conducted after ending the intervention (t_1) and as a follow-up (t_2). Concerning t_1 and t_2 it should be noted that centres have different approaches in methodology, so that common guidelines cannot be given.

Appendix E: Schematized process of data management

Step #	Task
1st step:	Data templates for all obligatory data will be provided for the raw data by COSIP-Hamburg.
2nd step:	Data templates have to be complemented by partners according to the specific needs of each partner.
3rd step:	Codebooks will be written by partners, assistance will be given by COSIP-Hamburg. The codebooks will be updated by partners throughout the process of data management.
4th step:	Data will be entered into the data templates by partners.
5th step:	Data will be continuously screened and cleaned by partners. Guidelines for this will be given by the coordinating center.
6th step:	Further data templates/ SPSS-syntax files will be provided by COSIP-Hamburg including reverse poling of items, the calculation of summary variables of the specific scales etc. This procedure will be administered after completion of screening and cleaning data at each center.
7th step:	All data files and codebooks will be collected in Hamburg, so a coordination of the use of data files will be possible.
8th step:	Free access to all data will be guaranteed by the coordinating center according to rules agreed on in the consortium.

Appendix F: Descriptive elements of data screening and cleaning

#	Task
A	Comparison of paper- and electronic-data-check In randomly chosen samples, a person other the person, who typed in data, counterchecks that values are correctly drawn from the paper-version of the questionnaire into the electronic data matrix.
B	Allocation of data within the matrix-check Experience has shown, that allocating persons, not families into the SPSS-matrix rows is a tricky issue for typing in data. Therefore, it is crucial to countercheck that.
C	Jumping-rules-check In several parts of our questionnaire (especially the BADO-C) a variety of jumping rules occur. It has to be tracked, whether data are entered according to the rule, which were foreseen for jumping-rules.
D	Impossible values-check Every variable has to be screened for values, which must not occur according to our coding-rules.
E	Plausibility-check
Ea	“Composition of family”-check Does the information, which the family gives on itself, fit to the returned questionnaires and the data, that was typed in (e.g. mother says she has only one child, but data in file convey, she has two)?
Eb	“Exclusion-/inclusion-criteria”-check Were data collected from children, who are not in our target age-group? Was material, which doesn’t apply to the respective person, given to the person?
Ec	“Contents of other questions”-check Detailed criteria have to be extracted from the contents of the questions yet. Two ways of checking will be applied, first, variables, which stand for themselves will be screened and mysterious values (e.g. menarche at age 4) looked at. Second, variables that go together regarding their contents will be checked for mutual plausibility (e.g. boy says, he experienced menarche).

Appendix G: Scientific standards of data management

Data masks and matrices

For all data that are to be compared and/or pooled within the project, shared data masks and matrices are prepared by the coordinating centre and was distributed to partners.

Codes

Whenever partners administer the same measures/measurement instruments, the items will be coded in the same fashion at all centers. Wherever standard instruments are used, codes will be taken over from these instruments. Instruments which are especially designed for COSIP (e.g. BADO-C) contain codes which are attached to items by the coordinating center. All partners are expected to stick to these codes. An exception is made for items, which contain answer categories, that are specifically tailored for each partner countries' needs (e.g. items referring to education).

Transformation of open format questions into codes

At some points in questionnaires, open format answers may be given by subjects. These data should be entered into electronic processing in the original version word-by-word. Wherever desirable these statements have to be transformed into codes. For some answers, a common way of transforming word-by-word statements into numerical codes already exists and is to be used (e.g. country codes are coded after ISO-alpha-3, medical diagnoses after ICD-10). Other questions may require a thought-out transformation of open format answers into codes. When depicting meaningful categories for coding, it is useful to first have a look at all given statements and then find more abstract categories, in which answers may be subsumed. This process of transformation should be well thought out and documented. At best, rules for coding should be set up, which tap most of all thinkable cases. These coding rules should be stated in the respective codebooks.

Codebooks

For all official data sets, written codebooks have to be kept, which give an overview of all variables contained. The codebook lists each variable and gives further information about them. Variables should be listed in the same order as they are in the data file. Moreover, the following information should be stated in the codebook for each variable:

- variable names (e.g. “EDUMO”)
- variable labels (e.g. “highest EDUcational level of MOther”)
- variable codes (e.g. “1” = male, “2” = female)
- computing of variable (e.g. is the variable a sum score of other variables?)
- how the variable had been asked for (e.g. in a questionnaire (which questionnaire?), interview, how was the question posed? etc.)

Partners are free to put additional information in their codebooks (e.g. Cronbach α, descriptives, outliers, scalings etc.). When data is pooled, common codebooks are shared among partners.

Calculation of Sum and Scale Scores

All calculations done in this syntax file including re-poling of items, recoding of items, calculation of scale scores or sum scores and the handling of missing values were done strictly according to the descriptions in the manuals of the respective instruments.

Missing data

Unfortunately, not all manuals are very explicit in describing what exactly is to be done with missing values. Generally, two major decisions have to be made, whenever missing values occur:

(a) how many missing values are allowed and you may still calculate sum/scale scores?

(b) if there are not too many missing values and you are allowed to calculate sum/scale scores, how are missing values adequately replaced?

For measures, who don’t cover in their manual how (a) has to be handled, we mostly used a proportion of 10% as the maximum allowed limit for missing values.

We relate this 10%-proportion to the number of items, a scale/sum score consists of. The missing values, which are still “allowed” (b), will be replaced by the intrapersonal mean of the other variables on the same scale. Whenever the manuals discussed the issue of replacing missing values, the method of choice is this calculation of intrapersonal means, so we decided to stick to this procedure.
The picture is different for scales, in which each individual answer is made up of a whole new content. However, the items of the CBCL and YSR, all make up new contents for themselves. Moreover, the CBCL/YSR may not be regarded as a classic psychometric measure, but may be viewed rather as a symptom checklist, in which each symptom really counts. Therefore, no replacement of missing values through means will be performed for these measures. Of course, this results in a slight downward bias for these cases, because missing values will be treated as zeros. However, the 10% criterion also applies to these measures, so if the bias would be too massive, no scores will be calculated. This way of handling missing values is a rather conservative one. The replacement of missing values by means reduces the score’s variance, which would only lead to an underestimation of effects in subsequent analyses. However, as we know from epistemology, the conservative approach is the method of choice in the social sciences.

Data archiving and processing

For data archiving and processing, the statistical package SPSS will be used, regarding literature citations, APA publication rules will be used by all partners.

Data storage and access

All collected data will be stored both on paper and electronically. It is each partner’s responsibility, to provide enough security for this data. Access should only be granted to members of the research team. All partners are responsible for making security copies of data sets. It is recommended that security copies are updated on a regular basis and that different places of storing (several different servers/computers, CDs) are used.

Anonymity

Wherever personal data are collected, anonymity is granted to the participating subjects and all information is submitted to medical secrecy. All questionnaires and collected material will be signed with a special code (COSIP-ID-code). For each centre, there will be only one list, which contains both names and addresses of subjects and their ID-Codes. This list is highly confidential and will be handed only to those persons who don't know these subjects personally. Wherever data are stored in quantitative data matrices, there will only be ID-Codes but no names or other data, which are prone to identify single subjects personally. When it comes to super- and intervision, all personal data are submitted to medical secrecy. Electronic transfer of data will strictly follow data protection guidelines. All steps are planned in a way that criteria for data protection are met. Subjects will be informed about anonymity and data protection issues and informed consent will be a prerequisite for participating at the study.

Psychometric measures

There are a several psychometric measures which are used mandatory at all centres. All partners have to make sure, that they include these measures in their study. It may happen that different versions of instruments (e.g. BDI or BDI-II) are used at different centres because official translations in the respective countries are based on different original versions. Whenever this is the case, each centre will use the version, that is most commonly used in the respective country and that is most up to date in order to guarantee a high chance of publishing results. Special attention has to be given on this aspect, when data are screened for their comparability. Therefore centres will inform the coordinating centre about the versions, their translated psychometric measures, which are used in the study, are based upon.

Translation and adaptation of psychometric measures

As different countries take part in the project, psychometric measures have to be used in different languages. Wherever possible, existing official translations of psychometric measures are used. If no translations exist yet, then project partners have to translate these instruments on their own. As a basis for translation, the original versions of psychometric measures should be taken (mostly, this will be the English-language version) and no versions which are already translations themselves. For the translation and adaptation of psychometric measures, the technique of translation and back-translation should be applied. Note that translator and back-translator are different persons and work independently on their translations. Moreover, the back-translator must not be knowledgeable about the original-language version of the psychometric measure. Translators should be experts in both languages. After translation and back-translation, the original version and the back-translated version of psychometric measures should be compared. The process of translation and adaptation should be repeated until both versions are equivalent to one another. Note that a translation which is very close to the original is desirable, however equivalence in content and meaning is more important than a word-by-word equivalence. Therefore, a committee of several experts in both languages and cultures should review the translation and may align undesirable expressions as a last step.

Appendix H: Scientific standards of data analysis

When data are analysed and interpreted, ways of data reduction and/or analysis should be carefully chosen and described. The way of data analysis should encompass a systematic step-by-step approach. Standards for this should be set up before starting the data analysis. Later modifications should be made possible, but justifications for this have to be given. Most important, the way of data analysis should be in line with the research questions. A rationale for the choice of data analysis should be given. If only a sub-sample of the data enters analysis, then the reasons for this should be stated. Again, careful consideration has to be given to possible biases evolving through this (Romer & Baldus, 2003). Whenever interpretations of data are given, these have to be substantiated through profound argumentation. Attention has to be given to any pre-assumptions, which may guide the researcher’s perception and interpretation. If possible, these pre-assumptions should be stated. In order to minimize biases, the researcher should also assume alternative interpretations. Strategies to ensure a reasonable validity and reliability of data analysis should be implemented wherever possible. Such strategies may encompass especially triangulation, the combination of qualitative and quantitative data and/or grounded theory approaches. Triangulation in this context means that one tries to develop different ways of data analysis and to compare the matches of the results. Moreover, the strategy of communicative validitation may be used: if possible, results of the qualitative analysis should be shown to the subjects examined and discussed with them. When results of prior analysis are integrated and discussed, special attention should be given again to the limitations of qualitative research, which in part are surely attributable to the inductive nature of qualitative research.

Appendix I: Control group brochure

COSIP

CHILDREN OF
SOMATICALLY
ILL PARENTS

Advices for families with children having a parent with acute central nervous system injury

Introduction

Injury consequences on family level

Spouse injury is an unhappy event reverberating to whole family. For the beginning, emotions like sadness, anxiety, agitation or even anger are dominant, naturally after such an event. Family life disorganize because of the suffering brought by the injury of the loved one, the necessity to stay beside him/her, hospital visit and an increase of all obligations by adding those formerly resolved by the injured person.

In this unpleasant situation, often called “crisis situation”, children are also involved and they may suffer even more than other family members. They may develop, like the healthy parent, some psychical disorders difficult to foresee before the event or they may increase the gravity of existing problems. Children of newly injured parents often have a rough time. They commonly experience feelings of depression and loss of attention due to the sudden, recent changes in their parent.

Children don’t understand much of what has really happened, especially if they are very young. They react intensely or moderately to some events, following the parent’s behaviour, especially those of the healthy parent. They conclude the gravity of a situation from spoken and unspoken words, from adults struggle and anxiety, from absence of the injured parent, from the changes encountered in daily routine.

At least for the beginning, the healthy parent is the one who has the most valuable information, children contact with the ill parent being mostly hasty, especially if the injured parent is in a bad situation or even in coma. Later, in case of satisfactory evolution, children will come to direct contact with the injured parent, who, during the disease development, will successively provide a series of often negatively or contradictory images.

Children – parent contact is often different from the one before and could become a source of worries, confusion, negative reactions towards the ill parent, due to the fact that children do not know what to think and how to explain his or her manifestations. Children lack quality information about the way that an injured person react and behave in different stages of the disease, as well as the way they should respond in order to diminish the parent suffering and bring some joy.

Children need continuous support in order to maintain their mental balance. They are more vulnerable and can become agitated, labile, freakish, negativist etc. Such changes appear because of psycho traumatic state, the lack of emotional control which is normal at their age and diminished parental support.

They might lose the pleasure to talk to their parents, especially if they are hiding too many things from them; they can also become very self-oriented. He can feel excluded from the important events of the family (which he perceived as not being fair) by hiding the evolution of the sick parent state. The child wants to take part in the family life, to talk freely and honestly about delicate matters, the family troubles, he needs to hear explanations and express his opinions, fears, worries. In the same time he needs understanding for his inappropriate behaviour during this period.

They like to help their family and to get involved, to do something for the ill parent and, no matter who their favourite parent used to be children are our closest family members and can become a source of moral support and even help the ill parent, or household.

But such services are likely to diminish in time, because children also have their own needs. They have to play and come back to former kids' activities. Yet they are not to be blamed, as they have done all they could possibly do and on the contrary, we have to thank them for how much they have done for their parents (although we could ask for more sometimes).

On the other hand, the ill parent’s situation improves in time. He can even heal completely or just have some flaws left, which must be accepted as such. The final state of the person will only be known after one or one and a half years, when all nervous rehabilitation and compensation processes of neuropsychic functions lost during the accident ends.

During the healing period the state of the acute central nervous system injured person can sometimes be deceiving. Although he seems healthy, he’s not the same anymore, he gets tired quickly, focuses more difficultly, memory is less focused and often forgets very easily, especially new data. Situations might be wrongly judged and often lack the ability to think about consequences properly.

The resistance to effort is also reduced, which is visible both during social contacts and other activities. Noise or loud music is more difficult to bear, and so are long parties and many persons around him. He loses interest in long, routine or too complicated activities and he becomes instable and quickly gets to other activities. This is why the moment when he decides to come back to the previous job has to be carefully chosen, as he needs a transition period with a reduced activity until he gets back to the initial stereotypes.

Emotions are expressed more obvious, he complains, gets angry quicker and he also gets over it in the same way. He can become jealous, selfish and eager to be always the center of attention. He can rarely become aggressive, but he can react toughly to contradictions because brain injury has caused loss of control over his emotions. There can also be headaches, dizziness, convulsive crises or other severe neuropsychic troubles.

In some cases the flaw can become permanent, which will make things worse for everybody. He can remain paralysed or have equilibrium troubles which prevent him from walking correctly. In some cases he might find it difficult to grab objects, practice self hygiene or other such basic activities, so he needs constant help from the others. In this context it is difficult to provide or receive long term help. The paralysed person can become capricious, unsatisfied by the way he’s treated or by the others’ devotion and attention.

In the context of psychic disorders things are more complicated, as the traumatized person can look as rehabilitated at first and he will be treated as ‘healthy’. “Noisy” psychical disorders worry the persons around and they do not seem understandable especially if they are expressed after a 3-5 month of good evolution.

In this case the help is more difficultly accepted and taken as an offence, because he cannot see things clearly and he can have the feeling he doesn’t have anything anymore, that the others have something against him or treat him like a kid, or even worse, persecute him. It is true that his position in the family lowers and he becomes a sort of child always in need for help. Even children’s’ contact with the ill person becomes difficult. The kids hardly realize when they should put an end to something or how to protect the ill parent and mostly forgets that his parent has become a sensitive person, and they might be easily hurt by rejections coming from the ill parent.

Life will go on for the whole family. In time, the emotions of the ones around the ill person will temper, but, if the above mentioned disorders do not improve, the ill person might become a burden to the family. Chronically ill people are capricious, they have high expectations, depressions or crying moments, but they can also be optimistic, trustful and co-operant.

Your responsibility as partner and as parent, extend on several levels. The main objective is to make family life as functional and good as possible, for the ill person, for you, as well as for the other family members, especially children.

We have prepared a set of suggestions in order to help you deal with this sort of difficulties.

Advices for spouse / healthy parent

Objectives:

1. regain control over your own emotions;
2. reorganizing your life and activities, based on the new context generated by the spouse illness;
3. adopting the proper behaviour towards your children so that they get over this difficult period.

1. Regain control over your own emotions

In this context when your spouse in a bad shape, you have to share the burden of negative emotions in order to face the pain caused by the illness of your dear one; you should share them with relatives, friends, colleagues and less with the children.

The discussions with the adults will be bring up not only the accident, the unhappy event, but also its consequences, what has happened afterwards, actual state of the spouse, as well as your own emotions, fears and worries. These discussions should be repeated anytime you need to talk or feel overwhelmed with negative, discouraging emotions.

Request for emotional support is not a luxury, it’s a necessity. The others’ support is the most valuable help, the most powerful force you can receive from them. It will be most times accompanied by concrete help; thus relatives, neighbours, other people can offer material and moral support; they can sacrifice a part of their time during the most difficult period of your spouse illness.

They will eventually go back afterwards to their own concerns and problems, but you should not feel betrayed, this was all they could give and it is well known that any help is welcome, as small as it is. So keep in touch with them, even if they do not actively help you. They are the source of moral support you can rely on in case more difficult moments are to come.

Don’t forget to talk as well about more pleasant things during your discussions with friends and relatives, so that they feel comfortable and become the old friend at least for a few moments.

After you feel released of the tensions, you must regain control over your present and future emotions, to try stopping the tears, the sadness and the despair.

You have become the family support now, the only one all the other family members rely and depend on.

You’re your best friend, so rely on yourself and try to be optimistic. You have to appreciate and protect yourself for every small thing you accomplish. Do not be harsh on you for what you haven’t succeeded, as the feeling of guilt discourage you and may cause useless trouble which might prevent you from acting efficiently.

2. Personal life reorganization

It is well known that an important event causes a disorder in your life as well; life has not the same rhythm anymore and can become extremely chaotic. New obligations become prioritary: going to the hospital, taking care of the ill spouse, losses, unexpected expenses, and loss of support from the partner you have received before getting ill. Usual activities have to be accomplished: the job, the household, the kids and even taking care of you.

In this context you have to re-organize your whole life, in order to handle all these aspects. This involves a good time management, so that you don’t neglect any of these activities; so you can start by thinking that you cannot achieve perfectly one activity and leave out another.

A good strategy would be to find resources to your parents, relatives, friends, even the children. They can help you accomplish these duties by sharing each a part of them. Be polite to those you ask for something, do not ask too much, do not complain if they refuse or don’t do very much, and just thank them for their effort. Complaints draw people away, while thanking and smiling makes them closer; so just try to keep up a corresponding figure, smile, even if you don’t feel completely satisfied with their efforts.

It is very important that you visit your dear one at the hospital and you stand by him/ her. Even if he is unconscious, try to talk to your partner, to hold his hand, as he may still understand the encouragement messages which strengthen the will to live. But take care so that visits to the hospital do not keep you from the other activities, which must not be neglected.

The job is also important and must be taken care of. If it is possible take any type of leave, especially during the worst period when the partner is in the hospital. But keep in mind that your job is the only income source for the family, so try to go back to work as soon as possible and fulfill your tasks; try to avoid leaving the work or excuses and don’t talk with colleagues too much about your problems, don’t complain too much as you can risk to become boring.

The household has to be kept as well in an acceptable state, so it is recommended to find a friend to help you with washing, cooking or other domestic duties. You’ll need extra efforts, but be careful not to exhaust yourself; so try to plan every step in order to save time and efforts.

3. Attitudes toward children:

In this difficult period, which could spread for some months to even years, especially if the injured person remains invalid, the children need also a lot of actions from you. It is important to have a better communication, to share the sufferings, building of a good fellowship with the children, to offer guidance and explanation, to discuss about the illness, and the possible reactions of the ill person and about the best way to behave in this difficult moments to calm down the situation and to cooperate in fulfilling of the daily duties. For the first stage it is necessary to communicate the bad news about the accident, about the ill parent current condition and possible consequences. After that, the children must be supported to discharge of those negative emotions, and to become to mentally integrate new situation. Then, they must reorganize their activity according to the new situation.

It is necessary to communicate to the children what was happening. You have to describe exactly what and how was happening, the present situation of the loved parent, the place where he is, if he can be visited or not, the possibilities of optimistic development. Don't fell overwhelm in that moments, try to be strong because the children estimate the seriousness of the situation from your reactions, emotions, and those reactions could be disproportionately.

The stage in which children pain is consumed will follow. They will ask questions, share their worries, their suffering. They need, and many times, can be listened while you make some household activities, or working in the kitchen. Pay attention to their suffering and be patient if they ask for many times the same question, it is natural.

Don't cry too much on their shoulder, because the power will decline and you could enter together in the fate's "victim" role. The encouragement it's a real medicine, the believing that the suffering's parent and you will manage to get over the difficult moment, must be transmitted strongly, especially if the illness is still uncertain. The neutral expression "we'll see", delaying the discussion about the decease, it's soothing. The children need calm and security, even if the family is in the bad period.

The child needs help to restructure his own activity according to this new situation. For his success he need to get first some explanations regarding the new emerged problems, connected to house holding, decreasing of help that he will get from his parents, the bigger responsibility that he will have, and the possible sacrifices like reduction of the playing time.

According to age, children could take some little tasks about self caring, hygiene, organize own room, trying to make homework alone, helping in house holding end little shopping.

This kind of change is painful but it must not include the whole children life. We have to ensure them a normal life without charging them too much with adult's worries. He needs to play everyday, especially if is smaller, otherwise we will have an unpleasant situation generated by frustration.

When the ill parent is returning home, the child should also take care of him/her. If tasks like talking, carrying a glass of water or other small but important obligations are proper, the personal hygiene of the ill and powerless parent might be quite disgusting for child and should be avoided.

To make change in someone's lifestyle, it needs patience, perseverance and tolerance; the need for freedom and desire of playing are powerful and they need to be fulfilled, at least partially. The constant trust in children is essential for helping them to cope with this situation, in this long way of reestablishment of the family's life equilibrium. Considering this, you need to possess the force to confess that you have weakness and hesitation moments, helping them to accept their own negative emotions.

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Bucharest 2002