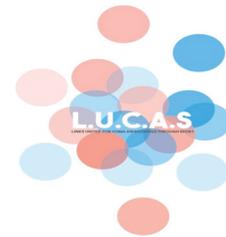


STRESS IN COMMUNICATION IN FAMILIES TAKING CARE ABOUT PERSONS AFTER COMA AWAKENING



Lina Miliūnienė, Liuda Radzevičienė
Šiauliai University, Lithuania

Turan Tolga Vuranok
University of Marmara, Istanbul, Turkey

Abstract

The article presents the results of the pilot research, which reveals the communication in a family taking care of their adult children after awakening from coma. The research is sponsored by Erasmus+ project “*Links United for Coma Awakenings through Sport*” No. 557075-EPP-1-2014-1-IT-SPO-SCP. Analysing the results of family communication and coping with stress qualitative research was applied. The results show that family members taking care about their adult children awakening after coma experience a different level of stress. Communication peculiarities reflect the lack of communication skills. The ways to cope with stress in the communication process are individual and based on self-realization and meeting of emotional needs of the family.

Keywords: *Parents, stress, communication skills, coma awakenings.*

Introduction

A traumatic brain injury can happen to anyone at any stage of life and it does not just affect individuals only. Due to modern technologies in medicine, significant number of persons that experienced TBI continues their life in other dimension. Mostly all scientists agree that after survival and awakening from coma these persons may experience serious long-term consequences and substantial costs associated with it (Tiesman, Konda, & Bell, 2011, cit. DeBaillie, 2014).

The problem of target group (families who take care about their family members who are awakening from coma after traumatic brain injury) is illustrated by statistic data. In Lithuania cranium and brain injuries happen more often than injuries of other human body

parts and these injuries make up 1/3 and 25-50% of all traumas. Every year the number of people who experience trauma is increasing and brain trauma is common at the age from 20 to 59. In 2010 the number of brain injuries was 123,1/100 000 of people, but mortality decreased to 11,3/100 000 of people. The frequencies of men's traumas are higher than those of women. From those who have experienced moderate brain trauma 7% dies, 70% suffers from neurological impairments. Statistic says that after severe brain injuries mortality is about 58% and 100% suffers from neurological conditions. New cases of disability each year are set up in 45/100000 of population (Lietuvos sveikatos statistika, 2012). There are no exact data how many people after TBI were in coma state. Usually after survival they are listed as patients with TBI. However, many of the patients with TBI were not in coma status, so the outcomes could be different. People awakening after coma face with serious changes in psychomotor functioning that create additional concern about their social integration and participation.

Long-term effects may include cognitive, physical, and emotional deficits. Cognitive deficits may include memory loss, concentration issues, or having a hard time solving problems. The analysis of the scientific literature (Fyrberg, 2013; Anderson, Parmenter, & Mok, 2009; McDonald, Togher, & Code, 2013) shows that those communication problems after traumatic brain injuries (TBI) are common mostly to all target groups. Mainly four categories cause problems of communication ability.

First, physical causes that deal with body motor functioning (moving from place to place, dressing, maintaining of hygienic habits, independent eating, hearing and visual impairments, and sensory-motor impairments that affect the ability to smell and taste, etc.

Second – what concerns cognitive skills that include memory loss, concentration issues, thinking, attention, hard time solving problems, etc. Often patients having partly retained intellectual capacities demonstrate cognitive fatigue that burdens everyday day life routine and retard the process of problem solving. Cognitive fatigue is a common long-term consequence of brain injury. Reduced attention and concentration leads to thinking indolence and create reasons for misunderstanding and irritability. The situation becomes more complicated if a person awakening after coma has speech violations such as aphasia, dysarthria and dyspraxia of speech (Foster, Amstrong, Buckley, Sherry, Young, & Foliaki, 2012).

The third category that influences the process of communication is emotional problems that manifest by the lack of self-control, impatience, decentralized and inadequate emotional reactions. Emotional problems are directly connected with the fourth – behavioural issues – persons' adequate interaction within environment. In long term rehabilitation parents could face with young adults' awakening after coma aggression, intolerance, emotional misbalance, and episodes of epilepsy as an outcome of TBI (Dyer, Bell, McCann, & Rauch, 2006, cit. DeBaillie, 2014). These problems could play the crucial role in person's social participation, ability to return to labour market or to live independently (Kosciulek, 1994).

Depending upon the severity of injury and its effects it transforms the life of the entire family. After an intensive rehabilitation period, everyday day life routine becomes more oppressive, unsure and leads parents to more serious psychological conditions. Parents passing through different stages of the acceptance of the child's trauma (or situation of denial) faces the question – how to continue meaningful personal and social life. This question concerns all family members according to their previous developed soft skills. In addition, the main instrument for dealing with everyday activities is communication that is described as complex skills for which many parts of the brain are responsible. Unfortunately, after traumatic brain injuries (TBI) directly or indirectly their functioning is affected. Families face with significant

changes in socioeconomic status as well. Along with the families' financial implications, the opportunity to obtain and maintain an employment place is strongly related to the quality of life and the well-being of all members of family (Tsaousides, Warshowsky, Ashman, Cantor, Spielman, & Gordon, 2009).

Most problems of communication occur in the nearest environment. As Verhaeghe, Defloor, and Grypdonck (2005) point out not the severity of the injury but the nature of the injuries determines the level of stress that families experience. Parents face with high level of anxiety and depression during the years following a brain injury, decrease in relatives' capacity for coping, particularly with emotional and behavioural problems. **Spouses** often feel socially and emotionally isolated, a couple's relationships turn to an undefined status because the main attention is focused on the children's problems. Lack of emotional interrelations between a couple often leads to the divorce (Calvete & Arroyabe, 2012; Ponsford, Sloan, & Snow, 2012). Family situation after getting into the new life dimension depends on many factors. Nobody is ever preparing of a family member's brain injury so the pathways are individual, requiring revising life values, skills and relationships. In this aspect individual's mental health in general becomes important. Individual's mental health could be affected by daily life, relationships and even his/her physical health. It also includes a person's ability to enjoy life – to attain a balance between life activities and efforts to achieve psychological resilience. Mental health helps determine how to handle stress, relate to others, and make choices. Over the course of human life experiencing mental health problems, thinking, mood, and behaviour could be affected. Many factors are associated with mental health problems, including biological factors, life experiences, family history of mental health problems, etc. (<https://medlineplus.gov/mentalhealth.html>). Therefore, this experience is shifted into the new situation taking care about a TBI family member.

The authors (Lequerica & Neumann, 2010; Ponsford, Olver, Ponsford, & Nelms, 2009) point out that the ability to create relationships based on flexibility helps parents, taking care about their adult children awakening from coma, to cope with problems (Kolakowsky-Hayner, Miner, Dawn Kreutzer, & Jeffrey, 2011). Parents have to be flexible to accept developing everyday situations not according to their suspense and rules but to be able to accept life view as a challenge.

The ability to communicate openly and honestly, directly expressing emotions both positive and negative and recognition of their own and whole family's emotional needs is the second condition for creating friendly communication environment. If a family demonstrates characteristics of flexibility and open communication, then it is possible that, after crisis of a family member's brain injury, a family can grow in strength through its way of dealing with it (Kolakowsky-Hayner, et al., 2011).

Object of the research: stress in communication of families who are taking care about their adult children after coma awakening.

Methodological issues and methods of the research: Research methodology is based on the issues of Theory of Reasoned Action (Ajzen & Fishbein, 1980, cit. S. Sutton, 2002) describing social-psychological research on attitudes and the attitude-behaviour relationship. The model assumes that most behaviours of social relevance are under volitional control, and that a person's intention to perform behaviour is the best predictor of that behaviour. Intention to behave in any way occurs due to two basic determinants: attitude towards the behaviour (the person's overall evaluation of performing the behaviour) and subjective norm (the perceived expectations of important others with regard to the individual performing

the behaviour in question). Generally, people will have strong intentions to perform a given action if they evaluate it positively and if they believe that important others think they should perform it (Sutton, 2002). This model seems to be the most suitable describing parents' ways of communication and understanding process of communication with family members awakening from coma.

Empiric data were collected using open questionnaires designed according to the analysis of scientific literature (Lequerica & Neumann, 2010; Fyrberg, 2013; DeBaillie & Kosciulek, 1994) compounding three main semantic blocks. Applying qualitative type of research communication peculiarities between parents and family members awakening from coma were revealed analyzing: 1) level of parents' stress; 2) activities that help family members to cope with stress; 3) ways to solve communication problems. Research data were processed using the method of content analysis.

The level of parents' stress was revealed using Perceived Stress Scale (PSS). Cohen's Perceived Stress Scale (PSS) is the most widely used psychological instrument for measuring the perception of stress (Cohen, Kamarck, & Mermelstein, 1983). It is a measure of the degree to which situations in one's life are considered as stressful. The items were designed to find out how unpredictable, uncontrollable, and overloaded respondents find their lives. It seemed to be important to set individual level of PSS because it might be directly connected with communication peculiarities. The items are easy to understand, and the response alternatives are simple to grasp. The questions in the PSS ask about feelings and thoughts during the last month. The research data on PSS results were described according to the test key.

Results of the research mostly reflect the tendencies of the analysed phenomenon because of too small sample.

The data were collected in June-August 2016 during therapeutic riding sessions in which parents take their young adult children for rehabilitation sessions through applied physical activity. Parents were asked to think and answer the questions during one month.

Sample of the research: 14 parents of young adults awakening after coma who were at the age of 42 to 63 years.

Discussion on the research results

Parents that took part in the research differ according to their age, educational level, professional experience and duration of taking care about their young adults children that experienced TBI. Ten mothers and four fathers participated in the research. The age of adult children was from 20 to 31.

Analysis of communication in families taking care about persons after coma awakening

Analysis of communication peculiarities in the families was done according to three aspects: 1) level of parents' stress; 2) activities that help family members to cope with stress; 3) ways to solve communication problems;

To reveal the peculiarities of communication in families taking care of coma awakenings young adults it is purposeful to understand family's stress level in their everyday routine. Long-term stress could appear because of facing with different types of problems that occur after family member's trauma that totally changed families' life plans and future suspense. Level of patents stress was set up applying Perceived Stress Scale (PSS).

Table 1. Stress perceived by family members

	Mothers	Fathers
Low stress (0-13 points)	2	1
Moderate stress (14-26 points)	5	2
High perceived stress (27-40 points)	3	1

All parents that participated in the research experienced different level of stress (Table 1). In seven cases, moderate level of stress was recorded. In addition, high perceived stress among parents was recorded more frequently than low perceived stress. Therefore, parents taking care about their adult children awakening from coma live in the situation of a permanent state of stress that reflects and influences communication processes within all family members. Experience of long-term stress affects cognitive processes; so ability to take decisions, to cope with action planning, memory and concentration problems affect the quality of communication and complicates the couple's relations.

Table 2. Perceived stress according to the age

	42 – 52 years	53 – 63 years
Low stress (0-13 points)	1	2
Moderate stress (14-26 points)	3	4
High perceived stress (27-40 points)	2	2

Person's age is another factor that could influence experiencing long-term stress. As the results show the age of the parents that are taking care about their disabled adult children has no obvious affirmation of significance. At any age the situation of child's disability, even if the child is already a young adult, provoke experiencing long-term stress for parents. The results of the research cannot be generalized because of too small sample, but in this particular case it was found that older parents experienced more stress (in eight cases) than younger ones (six cases). It could be because of parents' concern about the future of their adult disabled children, because of the changes of their own health, changes in economic and social status (Table 2).

The second aspect that was examined setting peculiarities of communication in families taking care about their adult children awakening after coma was *activities that help family members to cope with stress* (Table 3). It revealed that parents have no particular ways to cope with stress. Analysing activities of family members, mostly they are connected with everyday life routine. Women usually mentioned housekeeping works and garden works that in general are common for women's free time activities.

Table 3. Preferable activities of families to cope with stress

Category	Statements	Number of statements
Hobby activities	“to do garden works”; “time with a pet”; “knitting everything”; “decoration of my house”; “cooking for friends”; “everyday sports”; “collection of small vases”; “woodcrafts”	9
Relaxing time with family members	“The best time with my family”; “to be together at evenings”; “I want to spend more time with my son”; “Family creates relaxing time”; “I try to forget everything when we are together”; “... family’s understanding and support”; “I try to forget everything being with my family”; “wait for weekends to be with my family”	8
Cultural events	“to have opportunity to visit theatre”; “...ballet and opera”; “free exhibitions”; “fairs and markets in the city”; “to participate in city celebrations”; “participation in religious holidays”	14
Traveling	“to relax in south”; “to visit sister’s family” “excursions “to show the world for my son”; “traveling with my friends”; “to have holiday outside Lithuania”; “...opportunity to travel”; “to learn the world”; “travel”	7

Coping with stress shows that family members try to find ways in different places (outside and inside their living place) and using different activities. Four categories of activities that help to cope with stress were marked.

Cultural activity was mentioned more often than other ones as a way to cope with stress for both women and men (14 statements). Parents like to visit “...ballet and opera”; “free exhibitions”. It was mentioned that cultural events that take part in the city are preferable because sometimes it is complicated to go together with a disabled person. All the respondents mentioned city fairs and markets. It is a popular way of leisure time when family members participate in city celebrations, and positive emotional background of such events helps to feel socially involved.

Many respondents (9 statements) mention parent’s hobby as a relaxing activity coping with stress. It is a way of self-realization, the opportunity to retreat from problems, to feel emotional satisfaction, just to have a short rest from daily duties. Women indicate housekeeping as a hobby, meanwhile among men no one characterized housekeeping as a hobby. Women tend to find relaxing activities at home (housekeeping, garden works, handcrafts) more than men. Fathers taking care about their adult disabled children awakening after coma as a way of coping with stress indicate garden works, woodcrafts, collection of different things. They mentioned that this hobby serves to relax from emotional tiredness.

In spite of the fact that a stressful situation leads parents within family environment they indicate that time with family is one of the ways to cope with stress (8 statements). Even if women might choose any relaxing activities they want, mostly all of them prefer to spend time with their families. Positive emotional relationships create relaxing environment and it shows that successful marriage allows feeling happier and relaxed (“I forget everything being with my family”; “to be together at evenings”; “family creates relaxing time”). Feeling of belonging and being together with family allows parents feeling safe, confident and relaxed. Relax time together with family could be assessed as a rest from responsibility and concern when family members are busy with their everyday duties and works.

Traveling as a way to cope with stress is the fourth category that was marked analysing the research results. Nowadays we are used to thinking of travel as the ‘fun’ bit of life, but enjoyment is not a reason why it should not also do some very serious things for person. At its deepest level, travel can assist with psychological, social and emotional improvement. It can play a critical role in helping to grow into better versions of normal selves (Smith, Segal, Robinson, & Segal, 2016). Sometimes there is no difference for the respondents where to travel, the process of traveling is important as well. It means that it is needed to change every day routine to new challenges, experiences and different emotional situations that could help to cope with problems. In some cases it was mentioned that traveling must be together with family, in some cases with friends, or alone (“to go somewhere out from home”; “to travel the whole year”; “excursions in our country”; “to relax in south”; “to visit sister’s family”; “excursions to show the world for my son”; “to have holiday outside Lithuania”.

Ways to solve communication problems (Table 4). There are many different ways to solve communication problems in the family. The respondents were asked to indicate how they prefer to solve conflicts and misunderstandings that occur in daily communication process. Three categories were marked: constructive dialogues, way of persuasion, ignoring communication problems.

Table 4. Ways to solve communication problems

Category	Statements	Number of statements
Constructive dialogues	“we are talking”; “no one truth... common decisions”; “I try to argument my point of view”; “everything could be solved”; “long way to make a decision”; “I respect wife’s opinion”; “it is easy [...] we have the same view”; “consult with professionals”	9
Way of persuasion	“I know the situation better... so my decision”; “Sometimes it takes a long time to persuade the husband”; “there is the same idea in the head and discussions for weeks”; “it is hard to persuade my husband”; “now it takes a shorter time to convince on my choice”	12
Ignoring communication problems	“hard to start talking”; “I never pay attention to her silence”; “it is not a problem of communication usually it’s her naughtiness”; “never think that it is problem”; “all families have quarrels in their life... normal”	7

During the life span families create some kind of communication skills that help them to express themselves and listen to one another. By developing communication skills, partners are able to establish and preserve a loving, respectful relationship between two people who love each other. Wilson and Oswald (2005) point out that marriage makes people far less likely to suffer psychological illness and marriage makes people healthier and happier. Communication between family members directly reflects their relationships. Family that experiences their child’s brain trauma and difficult outcomes have additional aggravating factors that could change a couple’s relationships. It is common, that caregivers mentioned several reasons of their bad mood that could provoke problems of communication. The prevailing emotions, mentioned in the questionnaire were: tiredness, unhappiness, having a lot of troubles, worthlessness, loss of illusions and confidence in people, despair.

The results of the research show that couples solve problems of communication using the way of persuasion (12 statements). It means that couples estimate situations in a different way, in spite of long time spent together and common life values. The way of persuasion might

indicate different personal experience and relation to the occurred problem: “I know situation better... so my decision”. This way of communication shows that couples are open to listen to each other, there is no preconceived version of one’s own truth. The respondents mentioned that “sometimes it takes a long time to persuade the husband”, “there is the same idea in the head and discussions for weeks”; “it is hard to persuade my husband”.

Another way of solving problems is constructive dialogues. It could be assessed as the highest and most effective way to reach the goals experiencing the positive emotional background. Constructive communication in the families is rather a difficult process because of close emotional and personal relationships. Constructive decisions in a couple are usually mentioned among older couples: “we are talking”, “no one truth... common decisions”. To deal with communication problems sometimes couples “consult with professionals” but it usually deals with disagreements in taking care about their adult children awakening from coma. This way of communication shows strong and stable relationships of the couple, respect and confidence in the partner: “it is easy [...] we have the same view”, “everything could be solved”.

Ignoring communication problems (7 statements) usually reflects emotional tiredness (“hard to start talking”) and ignorance to the family situation in general: “I never pay attention to her silence”. Communication is a complex process, which involves many aspects of thinking and social skills but first reflects the problems of couples’ strength and affinity in personal level. Sometimes it shows the attitude to the partner: “it is not a problem of communication usually it’s her naughtiness”, “all families have quarrels in their life... normal situation”. Unfortunately, it is not so simple because there are many other factors at work besides knowledge and skills that affect not only the quality of a couple’s communication but also the quality of their relationship in general (Cobb, 2013). Such factors include commitment, willingness, intentions, desire, caring, and attitude. As the author points out some couples are so entrenched in negative intentions and attitudes that they are either unwilling to use what they know or somehow they use communication techniques in the ways that make matters worse.

Conclusions

We can talk about the tendencies, which were carried out in the research:

1. Parents taking care about their adult children awakening from coma live in the situation of permanent stress state that reflects and influences communication processes within all family members. At any age the situation of child’s disability, even if the child is already a young adult, provoke experiencing long-term stress for parents. Older parents experienced more stress (in eight cases) than younger ones.
2. It was revealed that parents have no particular ways to cope with stress. Mostly they are connected with everyday life routine. Cultural activity was mentioned more often than other ones as a way to cope with stress for both women and men. Traveling reflects a couple’s need to change everyday routine, experiences and different emotional situations that could help to cope with problems.
3. Couples use different ways to solve communication problems in the family. The respondents indicated three categories of communication: constructive dialogues, way of persuasion, ignoring communication problems. Most of the respondents mentioned the way of persuasion in the solving of communication problems in a couple’s interrelationship.

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STRESS IN COMMUNICATION IN FAMILIES TAKING CARE ABOUT PERSONS AFTER COMA AWAKENING

Summary

Lina Miliūnienė, Liuda Radzevičienė, Šiauliai University, Lithuania
Turan Tolga Vuranok, University of Marmara, Istanbul, Turkey

A traumatic brain injury can happen to anyone at any stage of life and it does not just affect individuals only. Scientists agree that after survival and awakening from coma these persons may experience serious long-term consequences and substantial costs associated with it that affects life of the family as well. Most problems of communication occur in the nearest environment. As Verhaeghe, Defloor, & Grypdonck (2005) point out not the severity of the injury but the nature of the injuries determines the level of stress that families experience. Parents face with high level of anxiety and depression during the years following a brain injury, decrease in relatives' capacity for coping, particularly with emotional and behavioral problems. **Spouses** often feel socially and emotionally isolated, couple's relationships turn to an undefined status because the main attention is focused on the children's problems.

Research methodology has been based on the issues of Theory of Reasoned Action (Ajzen & Fishbein 1980, cit. S. Sutton, 2002) describing social-psychological research on attitudes and the attitude-behavior relationship. Object of the research: stress in communication of families who are taking care about their adult children after coma awakening.

Empiric data were collected using open questionnaires designed according to the analysis of scientific literature (Lequerica & Neumann, 2010; Fyrberg, 2013) compounding three main semantic blocks. Applying qualitative type of research communication peculiarities between parents and family members awakening from coma were revealed analysing: 1) level of parents' stress; 2) activities that help family members to cope with stress; 3) ways to solve communication problems. Research data were processed using the method of content analysis. The level of parents stress was revealed using Cohen's Perceived Stress Scale (PSS) (Cohen, Kamarck & Mermelstein, 1983). It is a measure of the degree to which situations in one's life are considered as stressful.

It was set that parents taking care about their adult children awakening from coma live in the situation of a state of permanent stress that reflects and influences communication processes within all family members. At any age the situation of child's disability, even if the child is already a young adult, provoke experiencing long-term stress for parents. Older parents experienced more stress (in eight cases) than younger ones. It revealed that parents have no particular ways to cope with stress. Mostly they are connected with everyday life routine. Cultural activity was mentioned more often than other ones as a way to cope with stress for both women and men. Traveling reflects a couple's need to change everyday routine, experiences and different emotional situations that could help to cope with problems. Couples use different ways to solve communication problems in the family. The respondents indicated three categories of communication: constructive dialogues, way of persuasion, ignoring communication problems. Most of the respondents mentioned the way of persuasion in the solving of communication problems in a couple's interrelationship.