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The living standard of people after stroke

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Abstract

The living standard of people after stroke. – This article discusses the complex issue of life after suffering from a stroke. In recent years, it has been confirmed that cognitive impairment is common for people who have experienced a stroke. The stroke has also a negative impact on the whole family that is forced to adapt to the illness and its consequences. The relatives often deal with the new situation with difficulties and can even find themselves under a bigger pressure of events than the afflicted person. Nonetheless, the person who has experienced a stroke needs a huge emotional but likewise physical support from his closest ones.

Keywords: stroke, emotionality, life story

Klíčová slova: mrtvice, emocionalita, životní příběh

Nowadays, when people are concentrating mainly on their career or financial situation and its solution it is difficult to admit, especially when one is young, successful and perspective at work, that there might come a moment that will change his life entirely. A stroke affects in Czech Republic 30 000 people ever year and its aftereffects are not promising. Mostly they cause inability to be self-sufficient or physical and mental disability of the afflicted person. The treatment of that person is financially very difficult. Last year spent VZP insurance company in Czech Republic 482 millions of Czech Crowns for the treatment of more than 25 000 clients affected by stroke (National Insurance Company of the Ministry of the Interior, 2019).

The relationship of a person affected by stroke with his family, friends or colleagues might change because that person may become temporarily or permanently dependent on someone else's help. From this dependency can further result a disability. The family members of the person affected by stroke become, after his release from the acute medical or rehabilitation care, his informal carer responsible for fulfilling his daily needs, including the basic ones. In that moment it will become apparent how the partners, family members or colleagues will react to this situation. The person affected by stroke might get an insufficient social support from his environment or even may be forced to be relocated from his home to be live in an institution. A return to normal life is for a person after stroke very difficult, nevertheless, not impossible. It always depends on the effects of stroke on that person as well as on the person himself and his ability to 'fight' with the effects.

Important is also an awareness of one's own identity during and after stroke. This is always strongly connected with one's corporeality. A physical handicap limits and alters the

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person's perception of his own body image.[1] It also limits the experience with the environment one normally gains through movement.[2] There might occur a strong conflict between desires and wishes of the person after stroke and his realistic possibilities that are limited by his physical restrictions. The person may develop tendencies to hypersensitivity, egoistic behaviour or a misuse of the close ones for his own benefit. Sometimes can happen that in the attempt to surpass his limits, the person slips to a tendency to overestimate his own strength.[3]

The consequences of stroke are dependent on when did the stroke happened to the person, when was he provided with the first aid, hospitalization and rehabilitation but also on the extent of a brain damage. Many people after stroke have problems with movement, walking, swallowing or speaking. A weakness, incontinence and swallowing are during the treatment and rehabilitation period still regulated. Nevertheless, certain difficulties may remain for a longer period of time. Some other difficulties must be detected immediately, especially when a fatigue, partial memory loss or emotional issues occur.

The general changes in behaviour of some people after stroke manifest by a loss of interests in things or people they liked before. Others are impulsive and get easily upset. They experience an emotional lability that manifests by a frequent cry and laughter. Also the way how they perceive themselves might change after stroke. The fact that they are trapped in their own bodies, the shock when realising they are not self-sufficient and cannot communicate or work can all have a strong emotional impact on them. Even the alternations in the roles within the partners' or family life can cause a lot of issues for the affected person. Clinical depressions are, according to Šilhán, Perničková and Hosák,[4] a common consequence of stroke.

Hence, there are recommended different stimuluses in adequate levels the patient had positive relationships with from the past: the voices of his relatives, a favourite music or food, etc. Amongst common complication of this illness also belongs a depressive syndrome. A depressive syndrome, caused by stroke, is classified as an organic affective disorder. In scholarly press from abroad it is often referred as a *post-stroke depression*.[5] Between its symptoms belong a deeply depressive mood or a loss of ability to experience joy. Other symptoms are apathy, anxiety, self-assessment disorder, self-blame, helplessness, concentration and memory failure, cognitive disability, insomnia, lack of appetite and fatigue.[6]

[1] FIALOVÁ, Ludmila. *Body image jako součást sebepojetí člověka*. Praha: Karolinum, 2001; HOGENOVÁ, Anna. *K fenoménu pohybu a myšlení*. Praha: Eurolex Bohemia, 2006.
[2] *Ibid.*
[3] VÍTKOVÁ, Marie. Integrace dětí s tělesným postižením. In VALENTA, Milan. *Přehled speciální pedagogiky a školská integrace*. Olomouc: Univerzita Palackého, 2003.
[4] ŠILHÁN, Petr, PERNIČKOVÁ, Denisa, HOSÁK, Ladislav. Depresivní syndrom po cévní mozkové příhodě. *Česká a Slovenská psychiatrie*, 2012, vol. 108, n. 6, pp. 291–297.
[5] ROBINSON, Robert G., JORGE, Ricardo E. Post-Stroke Depression: A Review. *The American Journal of Psychiatry*, 2016, vol. 173, n. 3, p. 221–231.
[6] ŠILHÁN, Petr, PERNIČKOVÁ, Denisa, HOSÁK, Ladislav, *op. cit.*

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Research Process

In the research project *The significance of the support of communication skills by graphomotorics for people suffering from a severe aphasia in a context of the comprehensive rehabilitation and improvement of the living standard of people after stroke* (Donevová, Hájková, 2016–2020) we use a method of a real life story – a study of one's personal story, which is the most commonly used method in quality researches.[7] This method allows us to recall the past of a person after stroke and give his lifecycles a certain structure. The use of the method of a real-life story can also contribute to an empowerment of the people after stroke.

The aim of the research is to verify the influence of graphomotorics on a development of communication skills of the people affected by stroke who suffer with a high level of aphasia. The implications of the physical disability caused by stroke, this research focuses on, are mostly manifested in movement and coordination. In the most difficult cases they result in a complex immobility, they interfere with communication, self-care or motoric activities dependent on accuracy and speed. The research pursues to correct the deficit that in Czech Republic still remains within the research orienting on the connections between aphasic symptoms and intensive interventions in the field of graphomotorics and writing.[8]

The research is performed on eighteen participants divided into three groups. The criterion for the participation on the research is to experience the ischemic stroke that affected the dominant hand and caused aphasia, language and speech disorder. The key role in the research method plays a special pedagogical diagnosis of the fine motor skills[9] that is applied on the participants always straight after they joined the research. Based on the results of this diagnosis a methodology of graphomotor skills' development is further applied with a focus on a development of neuromuscular coordination, visuomotorics, sensomotorics and the support of skills important for regaining the ability to write.[10]

The graphomotorics test consists of 10 sections set into a time limit. There, a quality of the shapes' imitations with the focus on the line continuity and speed is being evaluated. The test is first set at the beginning of the research and further repeated after 6 weeks to control the progress. Within the period of six weeks there are 1.5 hours long sessions with the individual clients taking place daily. During them we assign and explain two graphomotorics exercises. The client is tasked to repeat those two graphomotorics exercises five times a day (continuously outlining the shapes with a use of a special pencil grip). During this graphomotorics exercises we are likewise concentrating on the communication skills in relation to the consolidation phase of aphasia therapy that is focusing on a replenishment and maintaining of the linguistics knowledge, ie. by practicing conversations.[11]

The initial attention is mostly payed on the highly automatized forms of language. These include messages that do not require any special effort, are phrased in a non-semantic

[7] HENDL, Jan. *Kvalitativní výzkum: Základní teorie, metody a aplikace*. Praha: Portál, 2008.
[8] OPATŘILOVÁ, Dagmar. *Grafomotorika a psaní u žáků s tělesným postižením*. Brno: Elporál, 2014.
[9] OPATŘILOVÁ, Dagmar, ZÁMEČNÍKOVÁ, Dana. *Možnosti speciálně pedagogické podpory osob s hybným postižením*. Brno: MU, 2008.
[10] *Ibid.* and OPATŘILOVÁ, Dagmar. *Pedagogická intervence v raném a předškolním věku u jedinců s mozkovou obrnou*. Brno: MU, 2010.
[11] CSÉFALVAY, Zsolt. *Terapie afázie*. Praha: Portál, 2007.

form and are often induced by the context of the situation. On one group of the participants we have the possibility to apply a robotic-assisted glove – Gloreha Professional II. (Gloreha: Gloreha Workstation, 2018) which uses repeated movements and patterns of the observation theory in an attempt to restore a mobility, improve the sensory sensitivity in hands and reduce their muscle tension. The device can work in few modes. The passive mode is applied on those rehabilitation's clients that have a fully reduced active mobility of their hands. The second mode is applied on those clients that have a partial hands' mobility.

The sensors in the robotic glove recognise when the client reaches the limit of his hand mobility and help him to finish the movement in the right direction. The third mode is devoted to clients with a full capacity of active hands' mobility. In this mode it is important to focus on the speed, precision of the movement and on the muscles' condition. This unique robotic device contains also a two-sided mode in which the client practices both hands at the same time. Whilst using the sensory glove on his healthy limb, the signals of the movement are being transmitted to the passive sensory glove used on the disabled limb. The movement of both gloves is hereby almost identical. The main aim of Glorehy Professional II. is a restoration of the optimal palm and finger grip – fine motor skills (BTL medical technique).

During the robotic rehabilitation and simultaneous practice of fine motor skills we are recapitulating, together with participants, certain simple concepts such as colours, animals, plants, household items, environment around us, days in the week, months in the year. After six weeks of robotic rehabilitation and practicing graphomotorics, with a focus on fine motor skills, we are connecting the words into simple sentences.

In the research *The significance of the support of communication skills by graphomotorics for people suffering from a severe aphasia in a context of the comprehensive rehabilitation and improvement of the living standard of people after stroke* is, amongst others, involved a lady who is four years after a stroke. She is functioning not only as a researcher but also as a participant. Her speech is still insecure due her suffering by aphasia. Her right arm is weakened. It was important to gain the trust of this client and explain the methodology of the graphomotorics exercises in which we are evaluating the quality of the imitated shapes and observing the line continuity and the speed. Another task is also a speech therapy. The robotic rehabilitation is applied on the inflicted dominant hand.

Within the participation research (a research in which are the participants involved in the role of researchers, author's note) we encouraged the client to tell us her story in which she recalled some memories and a variety of herewith associated situations. The return to the time before stroke in which the family operated on the basis of the best possible rules, planning, experiences and memories meant a heavy emotional burden for her. Many activities she did absolutely normally before stroke, such as doing sport, walking in nature, working, taking care of the family, functioning as a loving mother and wife, planning holiday or discussing the school results and hobbies of her daughters, ended with the effect of ictus. Essential was to direct the client to recount her experience in a form of a consistent story with all relevant events from the beginning, which means from the events before ictus, throughout stroke intervention and hospitalisation until nowadays, four years after ictus. The questions were thematically sorted into four sections – before stroke, stroke intervention, rehabilitation, current situation. The questions were shortened.

Our first question was: “Have you been able to influence or prevent the stroke by your conduct?” (R – Researcher). The client notes: “I often ask myself this question and am looking for the blame, why me?! I should have been more considerate about my health. I should not have underestimate the stress, fatigue and double vision, which appeared two days before the stroke. All of a sudden my whole life and the lives of my close ones changed!” (P – Participant). “The stroke caught you home alone without any possible assistance, how did you help yourself?” (R) “My husband was at work and my daughters at school, my phone was in the upstairs room. I could not get up from the floor so I decided to crawl for help on my back” (P). Today you are unable to answer how long did it take you to crawl to your neighbours. “At that moment I did not even know I was asking them for help and that they did not understand me. Then I fainted and woke up later in the hospital” (P).

The convalescence took six weeks and the rehabilitation started already in the hospital. “For the next convalescence stay I chose a rehabilitation institute that specialised not only on the physiotherapeutic care but mostly on the speech therapy. I knew I had a serious deficiency in my language skills that teased me a lot. After the rehabilitation stay I was looking forward to go home where my family, that was and till nowadays remains my huge help, impatiently awaited me. I had to rest a lot, yet, I was solving that situation together with my family. Talking was making me enormously tired. I wanted to read but after every sentence I was extremely tired and unhappy that my health condition was not improving the way I expected” (P). The biggest issue for her were basic terms. Initially, she could not name the days of the week, the months of the year or numbers. “I know that I am doing many language mistakes, that I have to correct myself and I am trying to do that. Often I am frustrated that I cannot find the adequate term in my vocabulary or the right word into the sentence or communication” (P).

The purpose of the next session was to determine the goals of our exercises. The important aspect for our client is, according to her own words, to improve graphomotorics. For the client it is essential to recover the language in conjunction with understanding and eliminate frustration and insecurity. We have available a robotic lab where a device Gloreha II Professional is located. Therefore, we are incorporating also the robotic hand rehabilitation to the exercise. The robotic hand’s rehabilitation practices the grip of the dominant right hand which is after IS still weakened. This type of rehabilitation is a completely new thing for the client.

In our discussions we were often recalling client’s family that was a big support and a motivation for her to improve in every rehabilitation. The client highlighted the thoughtfulness of her family. “I value that my husband and my daughters did not depreciate me as a person who will never get up on her feet anymore, will never speak or take care of herself. They helped me to regain a self-confidence, they help me in basic daily tasks like manipulation with the household items but only if I ask them to do so. I want to prove I can do it on my own” (P). This was a typical common issue at the beginning when the family, in an attempt to help and assist the client, made her feel like an incompetent and non-independent being which frustrated her a lot.

“At that moment I was not able to explain them the situation. I was angry with myself, with themselves and cried a lot. The only thing I was able to do was a rejection” (P). After a while the family understood that the rehabilitation was bringing some progress in terms of

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mobility and self-service. "I used every available moment for rehabilitation to show my family my health condition was improving. Obviously, every wobble, searching for a new motivation or even the correct timing of the rehabilitation methods was exhausting me emotionally. The frequent exhaustion, fatigue or loss of self-confidence required a large amount of patience and understanding from my family's side" (P).

Thanks the fact that the family is very sport-based, the client saw a great opportunity for improvement not only in terms of her physical but also mental condition. "The motivation that I will become fully self-sufficient once again was huge and the short walks in nature made wonders. My family began to asked me what I would fancy to do and we already started to plan family programs together. This was the biggest motivation of all to keep improving" (P).

The client decided to return to her previous job in office after three years. The family accepted and supported her decision. Also the fact that her decision was supported by her therapists she was visiting helped the client, much like the support of her colleagues that decided to facilitate her return back to work. The client was obviously afraid of a new people at work who did not know about her disability.

"Based on my experience I knew that someone did not care about my disability. Others were interested and cared too much. The most dreaded group of people for me was that one that was behaving very impertinently, almost nasty. They thought I was also mentally disabled. When I could not express myself, they immediately reprobated me not to talk to me ever again. I went through this all and my confidence often suffered. Hence, not only me but also my family was really nervous about my return back to work. Everything turned out well. After my return back to work I feel very well. With my boss we agreed on that I will no longer work with people that are coming to the office for information to avoid feeling bad about my remaining language issues. I am working in the office with great colleagues. So far, I do not prefer hand writing as I am aware that my fine motor skills, graphomotorics or even my text editing are quite weak. I am typing on PC, the program secures me a correction of the words and text editing. I am enjoying going to work" (P).

Currently the client attends a speech therapy once a month, an occupational therapy once a month, and graphomotorics and robotic therapies once in seven days. She enforces walking in the nature, riding a bicycle or skiing. She started to drive a car again. She is only afraid of the police checks on the road. "I am scared that if the police officers approach me in an attempt to perform an inspection and start to talk to me that when I reply I will come across as being under the influence of alcohol or psychotropic substances. When I am nervous, I cannot express myself coherently. Therefore, I would like to find a solution for my speech indisposition" (P).

Prospectively, it will be necessary to work on client's sometimes almost sceptical worldview she has due the fact her health condition is not progressing as quickly as it should. Nevertheless, the cooperation with her is really good. Thus, we decided to ask her to become a part of the research team. We presume, that her experience, skills and observations from the perspective of a disabled person will be really beneficial for the clients after stroke. It may function for them as a motivational stimulus for further therapy, rehabilitation and integration

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back to the society or even to the work process in searching for an interesting job. She accepted the membership in the research team.

Currently, we are working on the graphomotoric exercises. We are working on the passive and active hand's rehabilitation using the assisted robotic rehabilitation Gloreha Professional II. The speech production is still disrupted but the client is aware of the mistakes and immediately corrects herself without being asked to do so. We are talking freely about the current topic.

Conclusion

In the research project we would like to demonstrate that the influence of graphomotorics on the development of communication skills of people after stroke is significant, especially in relation to a connection of the association of changes in aphasic symptoms with the intensive interventions in the areas of graphomotorics and writing. To that we are using the above-standard possibility of robotic rehabilitation with the aim to restore mobility, improve the sensory sensitivity in hands and reduce their muscle tension. We would like to involve into our research more clients from around Kladno and Praha that experienced their first ictus of ischemic stroke that effected their dominant hand and caused aphasia.

They also should be after their first intervention of the interdisciplinary team – neurological doctor, rehabilitation doctor, physiotherapist, speech therapist and occupational therapist. The task of the special education teacher is, in our opinion, to connect the achieved results of the rehabilitation with an efficient special-educational diagnosis and intervention in the areas of fine motor and communication skills to start an improvement of the living standard of people after stroke. For people affected by stroke it is vital to enjoy every day of their lives and to be grateful for each improvement of their health condition. A return to a familiar environment, family, society and job represents for those people an enormous motivation, the most essential life's drive.

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