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Original research article

QUALITY OF LIFE AND NEEDS OF PERSONS WITH ACQUIRED BRAIN INJURY 3 TO 5 YEARS AFTER COMPLETION OF COORDINATED REHABILITATION

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Abstract

Objectives: The article points out the importance of coordinated rehabilitation in the personal social environment of people with acquired brain injury (ABI) after discharge from the treating medical facility. We compared the client's/patient's subjective perception of their quality of life and special needs several years after ABI to those same items immediately after the coordinated rehabilitation period.

Methods: The research was designed as a qualitative pilot study with auxiliary quantitative indicators. It was a longitudinal six-year study, concluded in April 2021 with a computer-assisted telephone interview (CATI) to determine the status and needs of participants. There were 17 client/patient participants.

Results: Research suggests that if therapy after ABI is not continued, clients/patients often reverse the gains made during 3-month coordinated interventions and, according to WHODAS 2.0, can return to pre-intervention levels within a year. Three or more years after ABI, clients/patients subjectively perceive that improvement in their condition has stagnated or has only slightly improved, and most reported a deterioration in their quality of life.

Conclusion: While participants were coping with their ABI, it was clear that long-term follow-up involving rehabilitation or at least longer-term professional help and support was desperately needed to help clients/patients maintain their initial improvements.

Keywords: *Acquired brain injury; Coordinated rehabilitation; Occupational therapy; Physiotherapy; Quality of life; Rehabilitation at home; Social work*

INTRODUCTION

With the increasing prevalence of patients after acquired brain injury (ABI), especially stroke (CVA), there is an additional need for quality health and social care (Bruthans, 2009). It is estimated that the number of people living with stroke in the EU will increase by 27% by 2047, mainly due to population aging and better stroke survival rates (Wafa et al., 2020). In the Czech Republic (CZ), rehabilitation for people after ABI is divided into four phases: acute, early, regional, and community (Maršálek et al., 2011). In 2019, the cerebrovascular section committee in the CZ analyzed factors leading to improved care for patients after CVA. A network of stroke centers was established, pre-hospital triage protocols for emergency services were introduced, a professional society issued recommended procedures, and the collection of quality indicators is now operational (Bar and Tomek, 2020). Treatment of patients in specialized stroke units has been shown to be beneficial due to the increasing number of those reintegrated into family and community life. The focus on returning to working life and the possibility to use the network of the pre-vocational centers are also essential (Angerová et al., 2021).

There is a trend in many healthcare systems toward prioritizing rehabilitation in the community setting or, more narrowly, in the home environment. This trend makes it possible to shorten the length of hospitalization and allow patients a quicker return to their social environment, which positively affects the success of rehabilitation (Nordin et al., 2015; Winstein et al., 2016). Despite this trend, a scoping review (Eliassen et al., 2023) shows a lack of continuity in service provision during the transition from hospital to home for patients after ABI. Research identified five categories of rehabilitation models that support transitions from hospital to home for people with ABI: multidisciplinary home-based teams, key coordinators, trained family caregivers or lay health workers, pre-discharge planning, and self-management programs (Eliassen et al., 2023).

A facilitative home environment has a positive effect not only on an individual's physical and psychological well-being but also on their participation in work, social, and civic life (Gibson et al., 2012; WHO, 2008). In the Czech Republic, the practice of coordinated rehabilitation in one's own social environment is lacking, and one of the fundamental reasons for this is the absence of good interconnections and communication between health and social services. The services needed, especially medical-social support, to allow patients to live at home are missing (Koubová, 2015). This situation persists even though stroke is the second leading cause of death worldwide and a significant cause of disability (Katan and Luft, 2018).

Day-care centers could also play an important role in the follow-up coordinated rehabilitation of patients after ABI, as reported by Angerová et al. (2021), focusing on a specific example in the capital city, Prague. Sládková (2021) mentions seven main principles of rehabilitation, suggesting it should be interprofessional, early, intensive, long-term, individual, coordinated, and accessible. This is often a very time-consuming and economically demanding process.

Despite significant improvement in acute stroke care, stroke survivors face lifelong consequences that impact daily activities and overall quality of life; however, the severity of these consequences can be reduced through rehabilitation (Branco et al., 2019; Khan et al., 2017; Kwakkel et al., 2017). Enderby et al. (2017) pointed out the necessity of individually targeted and personalized rehabilitation of stroke patients. According to Švestková et al. (2017), an individual approach is one in which the proposed rehabilitation plan and treatments correspond closely to the needs and abilities of the client/patient. Christiansen and Feiring (2017) stated that a patient's active participation is very important for effective rehabilitation, but at the same time, the rehabilitation team must listen and be responsive to the patient's needs and wishes.

MATERIALS AND METHODS

This research project, conducted by the Faculty of Health and Social Sciences of the University of South Bohemia, aimed to qualitatively map and quantitatively measure the coordinated rehabilitation of clients after ABI within their home environment. At the same time, using social work, physiotherapy, occupational therapy, medicine, speech therapy, and psychology methods and techniques, we assessed the significance of the help provided to clients in returning to their lives despite the limitations caused by ABI.

The research was designed as a qualitative pilot study with secondary quantitative indicators using methodological triangulation and "The QUAL-Quan Model" (Nastasi et al., 2007). It was a longitudinal study funded from 2016 to 2018. After 2018, additional data was collected, and various interventions were conducted regarding the client's continued time in the study. The study was completed in April 2021. Thus, the total duration of the study was almost six years. Participants were patients with ABI who were provided with three months of coordinated rehabilitation by a physiotherapist, occupational therapist, and social worker within their home environment; rehabilitation was performed under the direction of physicians. These patients were in the subacute phase of ABI, i.e., after discharge from the Rehabilitation Department of the České Budějovice Hospital. Enrolment in the study required the completion of the FIM survey (Chumney et al., 2010) and WHODAS

2.0 tests (Sládková, 2016; Üstün et al., 2010), see Table 1 for the baseline values. Ultimately, all patients from 2016 and 2017 whose health and social conditions allowed them to participate were gradually included in the study.

In total, 21 patients post-ABI were enrolled in the project. Of these, four ended their cooperation before the end of the project; this left 17 patients who finished. The mean age at baseline was 63.6 years, ranging from 35 to 86 years old. The structure of patients was as follows: four were diagnosed with a cerebrovascular accident (CVA) with right-sided hemiparesis, ten were diagnosed with CVA, resulting in left-sided hemiparesis, one had a traumatic brain injury with left-sided hemiparesis, one had multiple head trauma, and one had an aneurysm resulting in tetraplegia, see Table 1.

Patients underwent three months of coordinated and personalized rehabilitation at home and had follow-up visits after six and nine months. A final follow-up to assess client/patient status was conducted in April 2021. The assessment included semi-structured interviews conducted by social workers with clients and their family members.

During the study, individual professionals, i.e., PTs, OTs, and SWs, used different tools to objectify the status of clients (e.g., WHODAS 2.0, FIM, Barthel index, Timed Up and Go Test, Mini BESTest, Berg Balance Scale). Above-standard coordinated interprofessional care (i.e., physiotherapists, occupational therapists, and social workers) was provided to clients/patients directly in their homes. As needed, patients also received psychological or speech therapy as outpatient interventions (i.e., interventions that did not take place in the client's/patient's home).

The standard for each client/patient included two examinations by a rehabilitation

Table 1 – Structure of study participants at the time of enrolment

Patient	Diagnosis	Specific hemiparesis	Age	Sex	WHODAS 2.0 100%–0% (worst–best)	FIM 0 (max 126)	FIM 6
KL1	CVA	Right-sided	77	M	59.58	79	86
HBZ2	iCVA	Left-sided	52	F	39.58	113	121
ŠA3	CVA	Left-sided	71	F	53.23	105	106
KF4	iCVA	Left-sided	72	M	67.47	59	101
CM6	iCVA	Right-sided	78	F	8.23	115	125
RM7	iCVA	Left-sided	82	F	41.01	99	111
TM11	iCVA	Left-sided	74	F	26.39	107	123
MR12	hCVA	Left-sided	48	M	9.93	105	118
KT13	Traumatic brain injury	Left-sided	42	M	22.08	100	117
ML14	iCVA	Left-sided	58	M	34.72	66	75
BV15	iCVA	Right-sided	62	M	47.22	114	125
HJ16	iCVA	Right-sided	66	F	3.85	111	114
RB17	iCVA	Left-sided	77	F	15.97	92	111
KL18	Multiple brain injury	Multiple brain injury	35	M	6.25	90	116
RM19	iCVA	Left-sided	59	F	53.7	103	116
KJ20	iCVA	Left-sided	86	M	53.7	94	99
BP21	aneurysm	Tetraplegia	42	F	41.7	26	47

Note: iCVA – ischemic cerebrovascular accident; hCVA – hemorrhagic cerebrovascular accident;
FIM 0 – FIM at project entry; FIM 6 – FIM after six months.

physician (on project entry and again after three months of coordinated rehabilitation), 44 visits to a physiotherapist (two visits per week for the first three months, plus follow-up visits in the sixth and ninth months), six visits from a social worker (four visits during the first three months, plus follow-up visits in the sixth and ninth months), six visits from an occupational therapist (four visits during the first three months, plus follow-up visits in the sixth and ninth month; meetings for assessment and provision of rehabilitation aids for clients/patients were not considered part of the standard OT interventions and took place outside of the scheduled visits described above), and a single final follow-up distance contact to assess client/patient at the end of the project (conducted in April 2021). The final assessment was conducted using computer-assisted telephone interviewing (CATI) and did not involve a home visit.

The results from objective assessments (FIM, WHODAS 2.0), especially for measuring the effect of coordinated rehabilitation in individual persons, were statistically processed using Microsoft Excel 2010. Basic descriptive statistics were used to evaluate the results from the quantitative part.

Interviews were recorded and processed using the ATLAS.ti program. To define the needs of persons with ABI and relationships between needs, data then underwent axial coding (Hendl, 2016).

While the number of patients involved was sufficient for the qualitative processing of the research, the number was too low for statistical processing. Therefore, conclusions from the statistical analyses can only be considered pilot results that can be used to formulate goals for future research. Partial results from this study are included in other publications. This article focuses on the final assessment (conducted in April 2021) of client/patient status, obtained from the CATI, after clients/patients had been without coordinated rehabilitation for at least three years. All 17 participants or their families were contacted for the CATI, however, seven clients/patients could not be reached and were lost to the study.

RESULTS

Quality of life

We assumed that the client's/patient's quality of life, assessed using WHODAS 2.0, would be subjectively higher than that of the final evaluation after the coordinated rehabilitation, roughly three years prior. We assumed our clients/patients would have become increasingly well-adjusted to their situation during this three-year period. However, this assumption was not confirmed. Several patients perceived either stagnation or only slight improvement; however, to our surprise, most reported a deterioration in their quality of life.

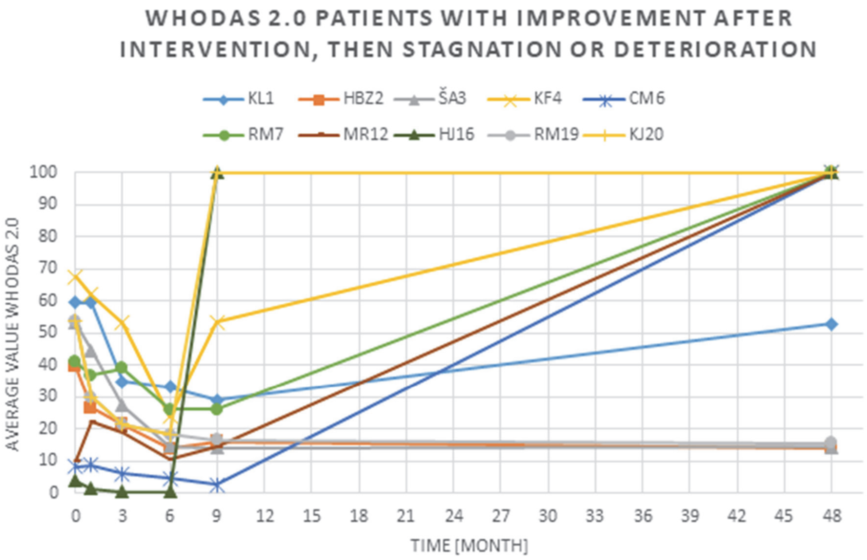
Our research suggests that if therapy is not continued, at least to maintain the client's/patient's condition, they can deteriorate back to the original level (according to subjective evaluation using WHODAS 2.0). After the 3-month intervention, most cases (without continued therapy) stagnated within one year, which was then followed by long-term deterioration (see Charts 1–2).

In some patients, we observed unexpected perceptions of quality of life, see Chart 2. From a long-term perspective, e.g., patient BP21 reported that their quality of life had stabilized. This was despite the patient, on their own initiative, taking part in long-term, at-home physiotherapy rehabilitation three times a week.

We can observe a comparable situation in patient ŠA3, i.e., long-term rehabilitation at a local polyclinic until January 2021. However, according to WHODAS 2.0 scores, they reported steady improvement in their quality of life during their rehabilitation, which is why it is included in Chart 1.

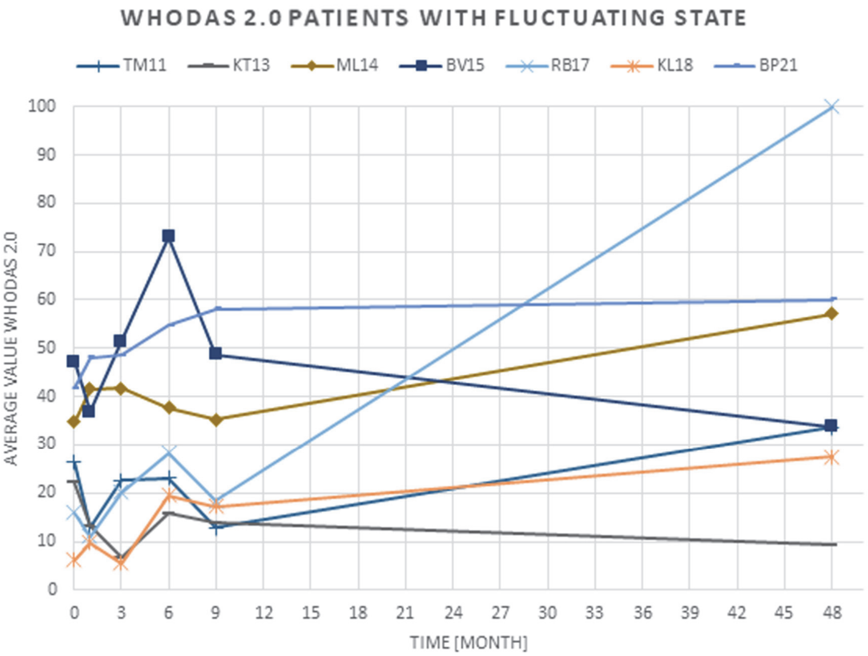
Patient KT13 reported modest, long-term improvement associated with their long-term rehabilitation and regular attendance at a special daycare center for people with brain injury.

The last patient reporting long-term improvement was patient BV15. This client/patient reported that when they regained their ability to drive a car, their sense of independence increased greatly, which significantly improved their quality of life.



A WHODAS score of 100 represents patient death. Scores closer to zero indicate patient satisfaction, i.e., without significant problems. Higher WHODAS 2.0 scores, i.e., closer to 100, indicate that patients were experiencing greater problems in areas of daily life.

Chart 1 – WHODAS 2.0 - Outcome results confirming the importance of coordinated intervention and further follow-up rehabilitation



A WHODAS score of 100 represents patient death. Scores closer to zero indicate patient satisfaction, i.e., without significant problems. Higher WHODAS 2.0 scores, i.e., closer to 100, indicate that patients were experiencing greater problems in areas of daily life.

Chart 2 – WHODAS 2.0 – Patients with fluctuating outcomes

Health status, coping with illness, and current needs

We further assumed that during the final client/patient assessment in April 2021, the overall health condition and the overall situation would not have changed significantly and that the clients would have already come to terms with their condition. This assumption was partially confirmed by most of the ten clients/patients contacted during the CATI. For example, Patient 18 stated: *"... I already feel that it's all good, but I know that it takes time, that maybe it will be like this forever."*

It is also necessary to mention that 7 of our original 17 clients/patients died before the April 2021 CATI. The higher average age of these at the time of entry into the study must be noted. These clients/patients were aged 75–89 years; however, one case was a 50-year-old with internal complications prior to the ABI diagnosis.

Semi-structured CATI interviews of ten clients/patients conducted in April 2021 found that most lacked any follow-up rehabilitation: *"I need to be more independent, brush my teeth, comb my hair, eat, my shoulder doesn't work"* (Patient 21). Interviews also found that clients/patients would welcome exercising at home rather than going to a facility: *"I've been to rehab twice; I don't want anything more."* The wife adds: *"My husband doesn't like the hospital environment..."* (Patient 14).

Most clients/patients would also welcome the possibility of intensive rehabilitation in a spa or inpatient facility: *"Mainly exercise... Overall, I miss the rehabilitation. Well, it was better after the spa, now it's got worse again. I miss rehabilitation. You know, I miss collective exercise too,"* (Patient 19) and *"I would like to go to rehab again and to the spa"* (Patient 13).

The table below summarizes each client's/patient's status at the final check-up and summarizes their needs in terms of occupational therapy and physiotherapy. It also includes information about the person who helps the client/patient and the specialized aids that the client/patient uses to make it easier for them to function in normal daily activities and contribute to an improved quality of life. In the last column of the table, we list important information about the follow-up rehabilitation, Table 2.

Comparison of needs over the years

An analysis of the results in the first year after the disease revealed seven needs – see Fig. 1. The need to find new systems of activities and the need to return to the state before the illness can be considered superior to the other five needs (Pechoušková, 2017).

However, the need to return to the pre-illness state resonates as the main one; clients/patients hope that it will be a quick process, and everything will be back to usual without major changes. For those who perceive that a full return is not yet possible, it is the need to find new systems of activities, at least temporarily, that comes to the forefront. At this point, from a psychological point of view, most people still do not want to accept the fact that the consequences can be permanent; the five stages of grief can also be applied to chronic illness, and according to Kübler-Ross (2015), they are as follows: denial, anger, bargaining, depression, and reconciliation.

When considering the need for help and the need for self-sufficiency, it may seem that, in some sense, they are at odds with each other. However, each is essential, and both are directed toward the need to return to the state before the disease and to find new systems of activities. Part of the need for help includes the need for family care, the need for professional advice and assistance, and the need for economic security. The need for self-sufficiency was highly valued in our sample and is related to the need not to burden their families. Part of the need for self-sufficiency is the need to walk and move about. Patients want and need to be independent, manage their self-care, and orient and navigate their environment.

The need for mental well-being is very important in the overall process of rehabilitation and was mentioned by almost all of our study participants either in general: *"I am nervous"*, *"I feel bad"*, *"I want to be happy"*, or specifically as the need for social contact, the need to access their environment, the need for mental health and personal security, and the need to see a path toward progress. Clients/patients also perceive the need for better health, mainly musculoskeletal, sensory perception, and cognitive functions. In this context, they mention the need for motivation and encouragement. Many patients expressed the need to be pain-free. They often cite headaches, stress, and fatigue in connection with medication side effects. Naturally, they consider an overall improvement in their health and condition to be crucial. They also mentioned the need for sufficient rest or sleep. Many of the needs, i.e., mental well-being, health, and a pain-free state, are connected with each other, as well as the other needs mentioned, and failure to meet any one of the needs leads to a deterioration in the fulfilment of others (Pechoušková, 2017).

Table 2 – Overall condition at the final check-up in April 2021 and needs in terms of physiotherapy and occupational therapy

Client	Current status (April 2021)	Needs/goals in terms of occupational therapy	Physiotherapy needs	Who/what helps (person + aids)	Information about the follow-up RHB
KL1	Loses interest in the environment, hallucinations, needs help from a psychiatrist	Self-care, relieving hand tremors, support for mental fitness	There is a total absence of exercise; they do not want to exercise alone at home	Granddaughter: walker, bathtub seat, anti-slip mat	Currently, without follow-up RHB
HBZ2	Stagnation, manages everything necessary	Self-sufficient, has no needs in this area	They don't want to exercise outside the home; they would welcome the possibility of RHB at home again	Partner	Currently, without follow-up RHB
ŠA3	Weak hand; knee buckles when walking, she goes to the spa, she was expecting improvement, but she doesn't go anymore	Improvement of finger strength, overall better hand motor skills	Swimming	Sometimes family	Until January, she had RHB at the polyclinic and also had RHB at the hospital
TM11	Neuropathy – problems with walking	Everything is managed, does not currently experience needs in this area	Overall, they are dealing with the possibilities of RHB, would like to go swimming, safer walking – *"So that my legs don't hurt and so that I am more confident"*	Son (shopping)	Currently, without follow-up RHB
KT13	Doing well, but misses their children	Short-term memory is affected in relation to normal functioning	Overall, any type of RHB or spa would be welcome, would also like to learn how to ride an electric scooter	Mother; knee brace, walking stick	In dealing with new housing with a nursing service, during the course of rehabilitation attended a daycare center for people with brain injury
ML14	Same status, no progress	Improving hand function	Keeping fit, staying on their feet, managing to move from wheelchair to bed, going out more	Partner, son; stairclimber, walker, roller, mechanical trolley	Uses the BTX app, doesn't exercise, doesn't want to go to the hospital or anywhere outside the home anymore

Table 2 (*continued*)

Client	Current status (April 2021)	Needs/goals in terms of occupational therapy	Physiotherapy needs	Who/what helps (person + aids)	Information about the follow-up RHB
BV15	No progress, but is already driving a car, and going shopping alone	Strength and function of the right hand; to engage in workshop activities	Improving the function of the right leg	Son, companion	Currently, without follow-up RHB
KL18	After hip surgery – positive benefit, memory problems, but feels satisfied	Can do everything needed, satisfied, does not have current goals	Does not feel the need for RHB, already considers their condition to be stable	Partner, son; walking sticks	Currently, without follow-up RHB
RM19	Rehabilitation is missing, attends spa	Feels self-sufficient	Safe walking (dizziness)	Partner, daughter living nearby; finger splints, walking stick	Currently, without follow-up RHB
BP21	Needs help with everything, but eating and hand-motor skills have improved	Self-sufficiency overall	Self-sufficiency – improvement of overall mobility	Spouse, parents; trolley, Motomed, ceiling lifting system	Secured home RHB 3 times a week

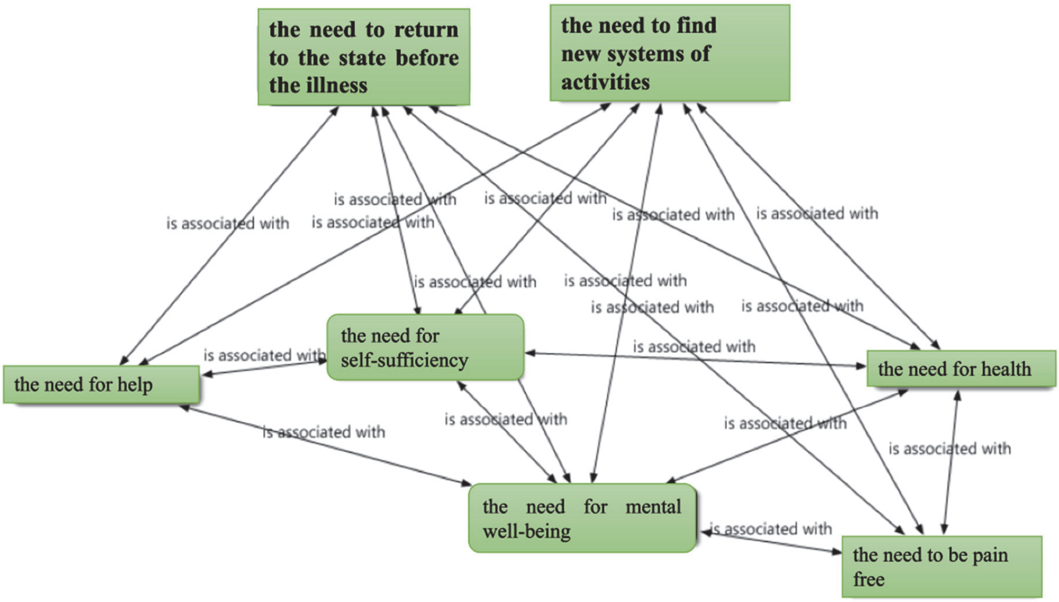


Fig. 1 – Patients' needs in the first year of illness, Elaborated in ATLAS.ti 7 (Pechoušková, 2017)

Over the course of 3 to 5 years, the needs of the clients/patients change and develop. They gain a different perspective on their condition, and they enter the period of reconciliation, which takes place gradually; while in some patients, reconciliation was evident, in others, as also observed by Kübler-Ross (2015), depression was still evident. The analysis of our CATI responses shows that the two most important needs seen originally were starting to change and evolve, see Fig. 2.

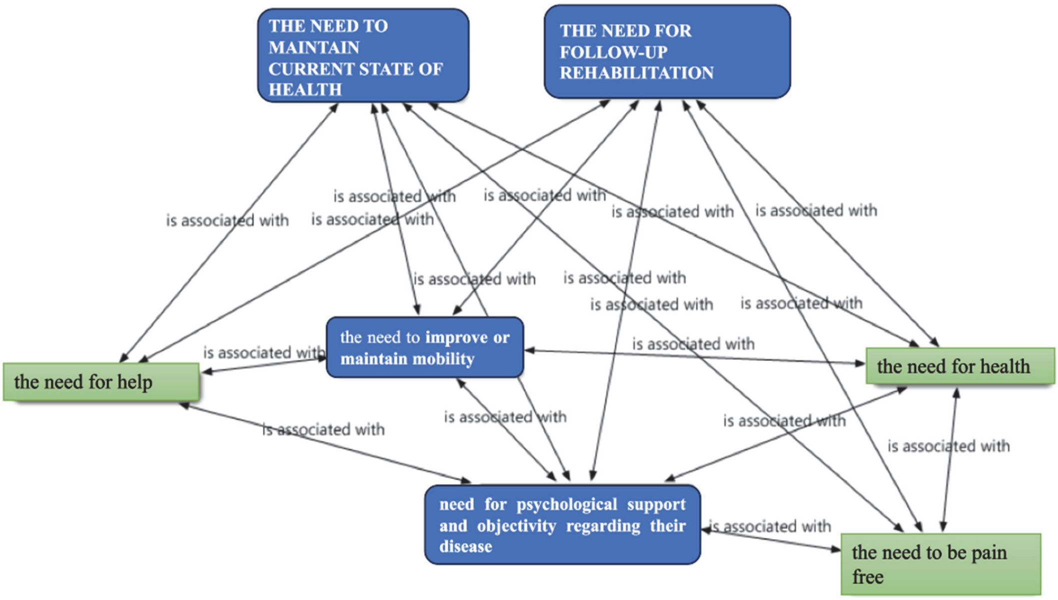


Fig. 2 – Patients' needs three or more years after ABI

The need to return to the pre-illness state was no longer noted; instead, there was the need to at least maintain their current state of health. The original need to find a new system of activities, which patients had already managed through coordinated rehabilitation, was replaced by the need for more or follow-up rehabilitation, which we can directly link to the aforementioned need to maintain their health condition and other subsequent needs. In terms of physiotherapy and occupational therapy, the need to improve or maintain mobility was vitally important, mainly since it was linked to overall mobility and gait, as well as motor skills of the hands and upper limbs in general. This was also strongly associated with the specified need for self-sufficiency.

The need for psychological well-being was always associated with the need for personal help, as well as help for their family. Over time, this need transitioned into a need for psychological support and objectivity regarding their disease. Since we observed that the state of health of many participants was not improving, and stagnation or deterioration prevailed in some cases, the availability of psychological support and related services focusing on the mental state of clients/patients should be a matter of course.

With greater disengagement from their conditions, many participants directly or indirectly stated the need for more leisure time and leisure activities. The interviews showed services focused on people after ABI were insufficient in the České Budějovice area.

Initially, study participants focused on the need for health and the need to be pain-free. These two needs do not resonate as much as they did after discharge from hospitalization, but due to stagnation or even deterioration in their health condition, many participants perceived these needs as unmet. With the passage of time, the need for help "in general" becomes more specific, i.e., the need for occupational, physical, and psychological help, as well as help in the form of compensatory aids or living space adjustments. Economic security had become less of an issue, as in most cases they were receiving long-term social support.

DISCUSSION

The quality of life and needs of clients/patients can evolve and change over time after ABI, but this is not always a positive change. In their systematic review, Hauger et al.

(2022) pointed out that studies report unmet treatment needs for patients after ABI in the chronic phase, including unmet family needs. People with ABI want to have normal personal and family lives in their apartment or house, in the company of their loved ones. Further, they want to have a job and decide for themselves how to spend their time. Some of these areas can be influenced by coordinated rehabilitation, but much depends on the approach and cooperation of clients, including their families. There is a knowledge gap regarding which type of interventions for persons with ABI are effective in mitigating long-term consequences (Hauger et al., 2022). We are aware that functional improvement can occur as a result of spontaneous regeneration. Therefore, further study and more extensive research on a larger group of clients/patients are needed to draw unambiguous conclusions regarding the long-term improvements associated with extended coordinated rehabilitation. Another limitation of the research is that the results of the intervention of individual experts cannot be separated from the coordinated intervention. Therefore, it is not possible to accurately evaluate the success of the intervention separately within the framework of occupational therapy, physiotherapy, etc. The results are evaluated and interpreted in a complex coordinated interprofessional approach. The model of coordinated rehabilitation with a team of experts visiting the client in his own social environment, as applied within the presented research, is possible in case of great support from the legislators. Changes in overall system, involving linkage of the health and social spheres, are necessary, especially in the Czech Republic. To evaluate the impact of 3–5 years without coordinated rehabilitation, we have established two assumptions below. The first focuses on quality of life (1), the second on needs and the clients'/patients' overall evaluation of their current situation (2).

(1) *Subjectively, the quality of life would be higher than at the last evaluation since the client has already become accustomed to their situation.*

This assumption was not confirmed since it was true for very few of our clients. Additionally, some patients had independently secured follow-up rehabilitation, and it was in these that we observed long-term improvement, as opposed to stagnation or deterioration, which was common for most others in the study group with continued rehabilitation. We noted that one's own sense of quality of life is often associated with the return to activities and may not be related to improvement of their condition, i.e., as feelings of independence increase, so does the perceived quality of life, as reported by patient 15, regarding being able to drive a car again: *"My condition is not improving much, but I can already drive myself in a car, I am now shopping for myself."* Patient 13 also perceives a better quality of life, feeling enthusiastic: *"Well, I have to show you that I learned to ride a bike, and I would like to try an electric bike or scooter."*

In patients who did not report any continuation of coordinated rehabilitation, the assumption was not confirmed, with some perceiving stagnation or only a slight improvement, while most reported some degree of deterioration. Research suggests that if therapy is not continued at least to maintain the client's/patient's condition, they will deteriorate back to original levels (according to subjective evaluation of the condition using WHODAS 2.0). After the end of the 3-month intervention, we can observe stagnation in most cases within a year, followed by long-term deterioration.

(2) *Based on the answers to additional CATI questions, we assumed that the state of health and the overall situation would not have changed significantly. However, we assumed that clients had already come to terms with their condition.*

According to the subjective evaluation of the quality of life in the form of WHODAS 2.0, stagnation or deterioration prevailed, but the second assumption was confirmed by most of the ten clients contacted 3–5 years after the end of coordinated rehabilitation. The answers from the clients below clearly indicate that they have mostly come to terms with their condition: *"I* [have accepted] *this way now, I am fine. I'm looking forward to the garden, gardening, and lounging"* (Patient 2). From the answers of patient 18, a sense of coping with the illness can also be deduced: *"I feel positive. I'm sorry* [it happened]*, but it turned out* [okay] *... I'm glad* [my condition has improved] *the way it is now.* [It means] *That I will take care of myself during the day.*

I know that even if I'm alone for a few days, I can do it."

Looking at the FIM values and perception of each patient's condition, we found a correlation: patients with low FIM values and overall lower self-sufficiency were less likely to report feelings of coping with their condition: *"... I don't exercise anywhere, only once every six months for Botox... I don't want anything more.* [The wife adds that the husband does not like the hospital environment; it has a negative/bad psychological effect on him]. *I want to be able to go out more. We walk in a walker every day... to manage* [with difficulty] *the transfers from wheelchair to bed"* (Patient 14, total FIM value: 66 on entry, 75 after six months). Patient 21, with the lowest overall FIM score (26 on entry, 47 after six months), also reported dissatisfaction: *"I wish I can't be at home alone for too long. When my husband goes for a run, my daughter or son has to stay with me."*

Although many answers suggested that patients had already come to terms with the disease, thus confirming the overall assumptions, we do not consider the confirmation to be unambiguous. We are aware that there is a need for further research on a larger group, ideally with various levels of self-sufficiency. When asked, *"How would you imagine your life right now if it were ideal?"* some clients reported a return to their pre-ABI state: *"I wouldn't have any paralysis or complications with my heart; that's what I'd* [be] *like"* (Patient 3). Or having a more active life: *"I'd like* [to have] *my driver's license, they took it away from me..."* (Patient 13).

We also discovered things clients/patients would do differently if it was within their power. Here, patients can be divided into three groups. Some feel guilt (their own or someone else's): *"That I would stop drinking. Or I wouldn't work so hard ... well, I don't want it to happen at all"* (Patient 15), *"I would change cardiologists. He is to blame for all of this"* (Patient 3).

Two patients still felt the need to return to their pre-ABI state: *"I would be happy if it could be returned overall. It won't be the way it was..."* (Patient 19). *"Well, I wouldn't want a stroke..."* (Patient 2). For others, there was a clear sense of resignation in their answers: *"I'm glad it's the way it is now"* (Patient 18). *"I don't think we did everything right, you directed us and then it was good"* (Patient 13).

However, clients lacked follow-up rehabilitation, guided home exercises, or spa treatments as expressed in their answers: *"I'm doing well, but I'd like to go to the spa for rehabilitation again. I'm bothered by my short-term memory, when I want to remember what I had for lunch, for example, I have to think about it a lot"* (Patient 13).

The fact that seven of the clients died is also significant and may reflect the absence of coordinated rehabilitation after three months.

The goal of the qualitative part of the research was not to create a grounded theory; the main purpose of the entire project was to focus on good practice and application of coordinated rehabilitation for people with ABI in the home environment. The term "intervention" is used in the text instead of "care", as "care" expresses passivity. The effort of rehabilitation is the active participation of the rehabilitated person in the process (Švestková et al., 2017). The intervention in the project was regular, with a pre-determined frequency of three experts (occupational therapist, social worker, physiotherapist). Psychological or speech therapy intervention was indicated by the doctor as needed. The coordinator of the team was a social worker. Due to the mentioned process, we can talk about "coordinated rehabilitation". The success of the intervention was measured by the FIM and WHODAS 2.0 tools, especially by monitoring the individual development of clients' functional status, while the number was too low for in-depth statistical analysis, as mentioned. The therapists' basic approach to achieving clients' goals was coordinated cooperation. Coordination and intervention were monitored and carried out by checking documentation, communication between the social worker and therapists, and mutual communication between experts. In this article, "follow-up rehabilitation" is any form of rehabilitation (including outpatient rehabilitation, physiotherapy in the home environment, spa treatment, etc.) that follows the termination of the coordinated team intervention within the project.

We established long-term cooperation with clients/patients after brain injury when they were "patients" of the Rehabilitation Department of České Budějovice Hospital. We performed all necessary initial assessments and had them sign an informed consent form shortly before the end of hospitalization. From a terminological point of view, after hospital discharge, they became "clients" of an interprofessional team of experts in a project focusing on coordinated rehabilitation at home. Therefore, we use the term client/patient in this article. However, individual professions may perceive terminological differences or possible inconsistencies in connection with established terms that they are accustomed to in practice. In their research, Soklaridis et al. (2017) describe problems with double terms. We encountered a similar phenomenon in our research, given that the project involved a variety of experts working together in an interprofessional team, i.e., doctors, occupational therapists, physiotherapists, social workers, and psychologists. We also consider a family member/caregiver as an important member of the team. As stated by Maršálek et al. (2011), these people can provide very valuable information about the patient and significantly contribute to the outcomes of the rehabilitation process. It also states that people important in the patient's life can provide long-term support, but at the same time, they themselves may need increased care, support, and sufficient rest. We can confirm this from our research project.

CONCLUSION

Research suggests that if rehabilitation therapy is not continued, patients perceive a deterioration in their quality of life, often regressing back to the original level (based on a subjective evaluation of the client's/patient's condition using WHODAS 2.0). After the end of a 3-month intervention, we observed stagnation of the condition in most cases within a year, followed by deterioration over the long term.

Semi-structured interviews of ten clients/patients conducted in April 2021, using CATI, showed that clients lacked follow-up rehabilitation. We found that the original goals of clients/patients that resonated immediately after ABI, namely quickly returning to an independent life and re-entering family, social, and economic activities, had changed over the years to an ongoing need for rehabilitation and a struggle to maintain health. CATI also found that clients/patients would prefer at-home exercise programs over facility-based programs (some clients/patients refused to attend such programs). Most said they would welcome an opportunity to attend intensive rehabilitation at an inpatient facility or spa. Seven of our original 17 clients/patients died before the April 2021 CATI.

Ethics

The study was conducted with the approval of the Ethics Committee of the FHSS USB (Faculty of Health and Social Sciences of the University of South Bohemia).

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Conflict of interest

The authors have no conflict of interest to declare.

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