

# The impact of Basic Body Awareness Therapy on balance and quality of life in survivors of hunger strike with Wernicke Korsakoff Syndrome

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## Key points of interest

- Basic BAT improves dynamic balance and quality of life of survivors of hunger strike.

## Abstract

**Introduction:** The aim of this study is to examine the short and long-term results of Basic Body Awareness Therapy (Basic BAT) on balance confidence and health-related quality of life in the people with Wernicke Korsakoff Syndrome (WKS) who survived hunger strike.

**Methods:** A single case experimental design was used in the study. Basic BAT was applied to 4 people as a group therapy once a week for 12 weeks. Balance confidence was assessed with the Activities-specific Balance Confidence (ABC) Scale and health status was assessed with Health-related Quality of Life Questionnaire (SF-36 Short Form). Assessments were done before treatment, after treatment, at 3-month and 6-month follow-up.

**Results:** 4 patients achieved clinically significant improvements on balance. All patients achieved significant change in physical functioning and role physical subcategories of SF-36. Visual analysis showed that the improvement in the patients continued after the treatment during the follow-up period.

**Conclusion:** Basic BAT is effective as a physiotherapy method in the treatment of cerebellar problems, balance disorders and gait incoordination seen in WKS. The Basic BAT method may provide a new perspective for the rehabilitation of survivors of hunger strikes with WKS.

**Keywords:** Hunger strike, Basic Body Awareness Therapy, Wernicke Korsakoff Syndrome, balance confidence, quality of life.

## Introduction

In 1996 and 2000, political prisoners in Turkey joined together in a prolonged hunger strike to protest their torture and ill-treatment in prison, (Gökmen et al., 1997; Temuçin, 2001). Hunger strikes are very serious and may lead to severe neurological disorders and even death. The natural result of prolonged hunger is Wernicke's encephalopathy and Wernicke-Korsakoff syndrome (Başoğlu et al., 2006; Gökmen, 1998; Kirbas et al., 2008; Temuçin, 2001). Wernicke Encephalopathy (WE) and Korsakoff Syndrome (KS), which

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are called Wernicke-Korsakoff Syndrome (WKS), are preventable, life-threatening neuropsychiatric syndromes caused by thiamine (Vitamin B1) deficiency (Isenberg-Grzeda et al., 2012; McCormick et al., 2011). WE is an acute syndrome, characterized by the clinical triad of nystagmus or ophthalmoplegia, mental state changes, and cerebellar dysfunctions (gait incoordination and trunk ataxia) (Sechi & Serra, 2007). KS is a residual syndrome in people with WE who cannot receive emergency and adequate treatment with thiamine replacement therapy. KS is characterized by cognitive and behavioural dysfunction in more serious cases (Arts et al., 2017; Isenberg-Grzeda et al., 2012). Although patients with KS continue implicit learning, they are unable to remember events that occurred half an hour prior (anterograde amnesia), but they are able to learn new motor skills or develop conditional reactions to stimuli (Arts et al., 2017; Sechi & Serra, 2007). Chronic alcoholism has been identified as the most common etiological cause. In addition, KS may develop in people on long-term hunger strikes, with anorexia nervosa, bariatric surgery, cancer deficiency with thiamine deficiency, vomiting, malnutrition, and who reject nutrition for various reasons (Isenberg-Grzeda et al., 2012; McCormick et al., 2011; Sechi & Serra, 2007).

A hunger strike situation negatively affects the health of the survivors of hunger strike and leaves irreversible damage. After a long-term hunger strike, the determining finding in the chronic period - the initial period - is WE and WKS (Başoğlu et al., 2006; Gürvit, 1997). Cerebellar dysfunction and ataxia, symptoms of WKS, have been reported to improve gradually in some cases while permanent in some others (Başoğlu et al., 2006; Gökmen, 1998; Kirbas et al., 2008; Temuçin, 2001). People with WKS who have with chronic ataxia typically stand with a broad support surface and

tend to fall forward or backward if they cannot support themselves physically. It has been observed that basic posture and walking take place with insecure, slow and small steps. Even in its mildest degree, performing the "tandem" gait was found to be difficult. Decreased associate arm movements and mild anteflexion posture are observed during gait (Gökmen, 1998; Temuçin, 2001). Ataxia and balance disorders affect the functional capacity of people with WKS, limit their independence in daily life activities and impair their quality of life (Sanchez-Lopez et al., 2017). Progressive long-term neurological conditions can affect both physical and emotional well-being with reduced health-related quality of life and require multidisciplinary health and social care interventions (Calvert et al., 2013). The imbalance is the most important factor in independent walking and daily activities. The main purpose in restorative physiotherapy is to improve balance and posture reactions to external stimuli and gravity changes, and to improve the quality of life by increasing people's independence whilst performing daily activities (Armutlu, 2010). Intensive rehabilitation programs are based on static and dynamic balance control, trunk stabilization training, multiple joint coordination exercises, and strategies to prevent falling (Freund & Stetts, 2010; W. Ilg et al., 2010).

Basic BAT is a method that focuses on postural stability and dynamic balance. Movements are made by maintaining the body's balance line and the ability to use stability limits (A. Gyllensten, L. et al., 2019). This method includes lying on the ground, sitting, standing exercises and walking, relational movements, as well as the use of sound and massage. Basic BAT exercises represent a sum of daily movements. Movements are made simple, small, soft, rhythmic and can be adapted to daily movements (Liv H. Skjaerven et al., 2018). When doing the movements, it is important for the individual to

pay attention to both "what they do" and "what they experience during the movements". Basic BAT also stimulates the awareness and movement performance of the individual. The therapist encourages the person to act with more appropriate postural control, balance, natural breathing and coordination (Gyllensten et al., 2003b). In Basic BAT, the aim is to establish relation with the ground (grounding), increasing stability in the centre line, breathing and flow; to improve sensory-motor awareness, dysfunctional movement patterns, perception of habits and motion control (Gyllensten et al., 1999). Positive effects of Basic BAT have been shown for improve quality of life, improve self-efficacy (Catalan-Matamoros et al., 2011), body awareness, balance and movement control (Gyllensten et al., 2003b; Hedlund & Gyllensten, 2010). In people who had suffered a stroke, Basic BAT, was important for balance function and daily activities (Ahn, 2018; Lindvall et al., 2016).

Gait incoordination, imbalance and fear of falling are the most difficult clinical tables in ataxic people with WKS. These syndromes cause serious deficits in the physical, psychological and social dimensions of life, leading to a significant decrease in daily activities and quality of life (Sánchez-López et al., 2017). The aim of this study is to evaluate the effects of BAT intervention on balance confidence and health-related quality of life in people with WKS.

## Method

### *Study design*

The study was originally designed as a controlled cohort study for the effectiveness of the BBAT approach in people with WKS. Participation in the study was low due to reasons such as participants not staying in the same place for sufficient time, financial problems,

lack of permission from their jobs, not accepting new and different treatments, and the long duration of body awareness training. The study design was changed and arranged as a single-case experimental design (SCED). To examine the effect of Basic BAT for patients with WKS, an A-B-A design with a three- and six-month follow-up was applied. Data from self-report measures were collected at baseline (A: pre-treatment, the first day of treatment), after 12 weeks, at the end of intervention stage (B: Post-treatment the last day of treatment), at the second baseline, at 3 month follow up (A1) and at 6-month follow up (A2). All patients received Basic BAT one day per week for 12 weeks. Each session lasted for 90 minutes. Qualitative data of patient perspectives from interviews was also collected but is not included here. The evaluations and Basic BAT application were carried out by an experienced physiotherapist on Basic BAT. Statistical analysis of the study was done by another evaluator. In the first baseline phase (pre-treatment) patients did not receive any physiotherapy.

After baseline assessment, during the intervention phase, Basic BAT was applied to four patients as group therapy. Those with issues with standing independently did exercises by standing next to the grab bar. The Basic BAT group therapy was led by a physiotherapist who has therapeutic competence as a "B-BAT Therapist". The program included basic movements to experience relationship with the balance line, grounding, awareness of stability limits and movement coordination. Specifically, the purpose of each therapy session was to increase the person's physical, physiological, emotional and existential awareness (Gyllensten et al., 2003b). Slow and rhythmic movements were performed by combining with breath and sound. Patients were instructed to focus their attention on their body and breathe when doing exercises. Each session consisted of six parts

(table 1). Group therapy is intended for patients to provide social support for each other, to share their experiences, and to gain awareness both individually and as a group. Group therapy began by focusing on the spine to regulate muscle tone and breath, and then continued with body alignment. The exercises were done whilst keeping the balance line within stability limits in sitting and standing positions. The sessions ended with special massage techniques performed by patients on each other. People were asked to implement and to integrate their new movement principles they experienced during each therapy session into daily life movements and actions.

#### *Participants*

Four patients from the 1996-2000 hunger strike, who were followed by the Human Rights Foundation of Turkey (HRFT), were

included in the group study between March 2016 and December 2016. Written informed consent forms and information in Turkish were provided, read and signed by the patients. The Human Rights Foundation Ethics Committee granted approval for the data collection based on the ethical principles of the Declaration of Helsinki (No: 2020/10). Inclusion criteria; those with cerebellar ataxia with WKS diagnosed by HRFT medical council, who were able to stand without support according to [Functional Ambulation Classification (FAS)>0] and who accepted to volunteer in the 12-week study. Age, vitamin-free hunger duration and disease duration on people diagnosed with WKS after the hunger strike is given in table 1. Vitamin supplements were used to prevent worsening of health conditions of hunger strikers and durations are recorded. All had gait and balance dis-

**Table 1.** Basic Body Awareness Therapy Programme

Duration: 90 minutes

1) Meeting patients and physiotherapist	Talking about his/herself and the weekly movement experiences
2) Lying down exercises	Body scanning, breathing exercises, opening/ closing exercise, comfortable stretching exercises
3) Sitting Exercises	Body alignment, breathing exercises, pushing the floor with feet one by one whilst keeping the balance line
4) Standing Exercises	Body alignment, awareness of stability, of limits, going up-down on balance line, weight transfer on wide step, turning coordination, symmetrical and asymmetrical arm swing with rhythmic knee flexion, wave and push-hands exercises
5) Related exercises and massage	Sitting massage to each other
6) Ending the session	Sharing reflections about experiences of the session with the group.

orders. Three people were independent in their ambulation, and one person required a walking aid.

#### *Instruments*

The effect of Basic BAT was evaluated with the Activities-specific Balance Confidence Scale and Health-related Quality of Life Questionnaire (SF-36).

*Activities-specific Balance Confidence (ABC) Scale:* Self administered 16-item numerical assessment scale. It evaluates walking balance (such as walking around the house, walking on icy ground). A value of 0 indicates that there is no balance, and a value of 100 indicates that the activity shown is completely safe. It was translated into Turkish and a cultural adaptation, validation and reliability study was carried out (Ayhan et al., 2014). It shows excellent internal consistency ( $\alpha = 0.95$ ) (Karapolat et al., 2010).

*Health-related Quality of Life Questionnaire (SF-36 Short Form):* The questionnaire was translated into Turkish including a validity and reliability study (Kocyigit et al., 1999). It consists of 36 items that measure eight subscales; Physical Functioning (PF), Role Physical (RP), Social Functioning (SF), Mental Health (MH), Role Emotional (RE), Vitality (VT), Bodily Pain (BP), General Health (GH). The subscales evaluate health between 0-100 and an increase in score represents an improved quality of life (Kocyigit et al., 1999). The standard version of SF-36 evaluating the last four weeks was used in this study (Demiral et al., 2006).

#### *Visual and statistical analysis*

The ABC Scale, PF and RP scores of the patients are provided in the figures below, respectively. Reliable changes for other SF-36 subcategories were not given because they were not significant (Table 3). In the visual

analysis of the figures, only the changes in the levels were calculated due to the low assessment points in each phase. The trend overlap and stability assessment points are not given because they were insufficient.

The method of separation from dysfunction was used to determine whether reliable changes in the ABC Scale and SF-36 scores of people were clinically significant. In general, this method is assumed to show a clinically significant improvement when a person begins treatment in a dysfunctional state and ends in an improved functional state. Specifically, a clinically significant improvement was defined as a robust improvement of two or more standard deviations in each measure of the person's pre-treatment (and follow-up) scores (Kazdin, 2011).

A reliable change index (RCI) was calculated for each measurement to determine whether changes in scores were reliable, and not due to standard measurement error. This is calculated by dividing the difference between post-treatment (and follow-up) and pre-treatment scores by the standard difference error between the two scores. When RCI is greater than 1.96 or lower than -1.96, a reliable change has occurred (Jacobson & Truax, 1991). Descriptive statistics were given for demographic data. For the variables determined by the measurement, the study calculated the mean and standard deviation. Windows based SPSS 23.0 analysis program was used for statistical analysis.

#### **Results**

4 individuals (3 female and 1 male) participated in the study. Their average age is  $47.0 \pm 8.52$  and their demographic information is given in Table 2.

Visual analysis of patients' ABC score and SF-36 subcategories scores in measurements revealed a clear trend towards improve-

ment before and after treatment (Figure 1, 2 and 33). In Figure 1, pre-and post-treatment level changes of people's ABC Scale scores are 39.7% (improving), 21.2% (improving), 111.5% (improving) and 34.5% (improving), respectively.

Reliable changes were observed in ABC Scale, PF and RP measurements, both before and after treatment (Table 3).

Clinically significant improvements were observed in subdomain PF and RP measurements of SF-36 and ABC Scale. Improvements in the remaining measures –MH, VT, RE, SF, BP and GH - have also been seen, but have not been so robust. The first hypothesis is that balance and physical processes of the study will improve significantly after treatment and will be continued in follow-up (Figure 1-2).

**Table 2.** Socio-demographic information of the participants

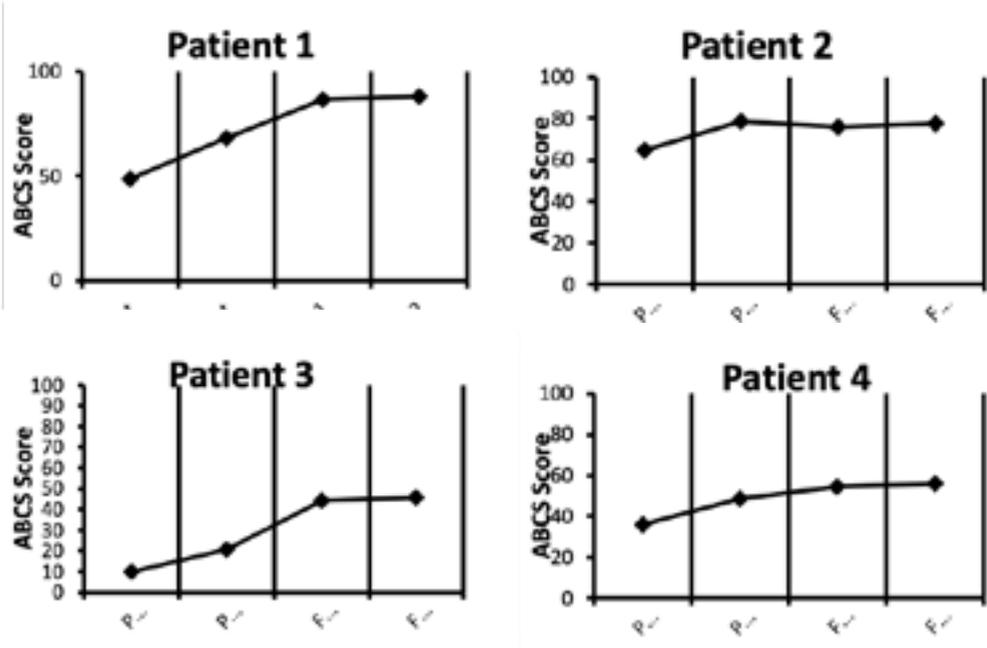
	Gender	Age (year)	Hunger duration (day)		Disease duration (year)
			In 1996	In 2000	
Person 1	F	39		93 / vitamin-free	15
Person 2	F	44	70 / vitamin-free		20
Person 3	F	59		244 / vitamin	15
Person 4	M	46	59 / vitamin-free	174 / vitamin	15

**Table 3.** Descriptive statistics and RCI&RC results (n=4)

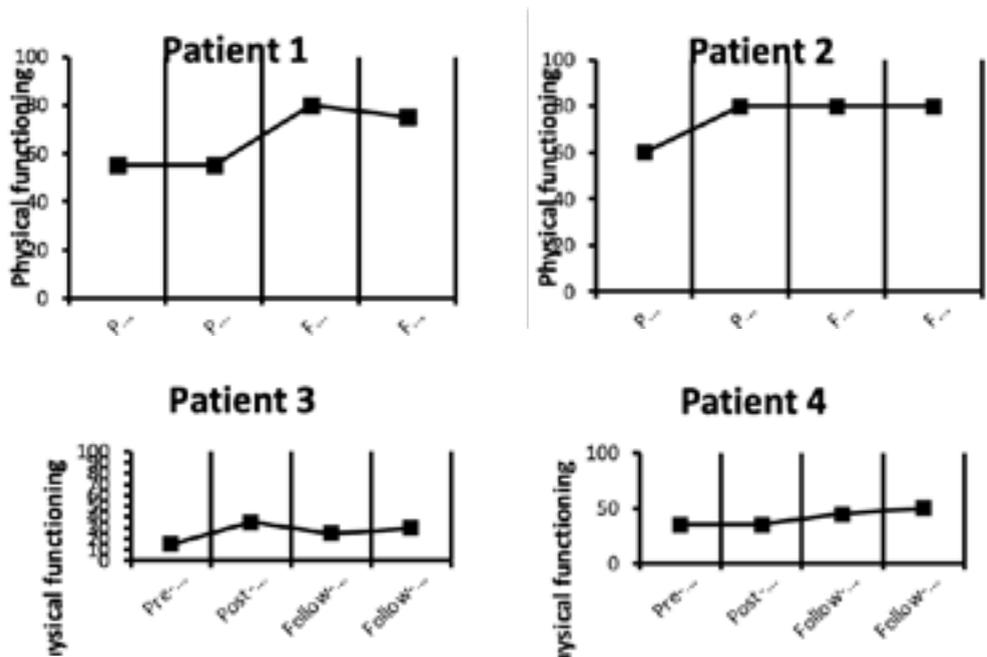
	Pre-Treatment Mean (SD)	Post-Treatment Mean (SD)	RCI (RC)
ABC Scale	39.94 (23.31)	55.06 (25.52)	14.45 (2.05)*
SF-36 Subscales			
Physical Functioning (PF)	41.25 (20.56)	51.25 (21.36)	8.06 (2.27)*
Role Physical (RP)	12.50 (25.00)	31.25 (31.46)	12.00 (3.06)*
Mental Health (MH)	41.58 (41.97)	58.38 (16.91)	69.78 (0.47)
Vitality (VT)	47.51 (13.23)	56.25 (10.31)	21.68 (0.79)
Role Emotional (RE)	69.00 (15.45)	72.00 (14.24)	11.33 (0.52)
Social Functioning (SF)	47.38 (12.30)	59.88 (25.6)	14.86 (1.65)
Bodily Pain (BP)	78.13 (9.40)	70.0 (5.34)	9.03 (-1.76)
General Health (GH)	41.25 (11.09)	42.5 (8.66)	12.30 (0.2)

RCI: Reliable change index, RC: Reliable change. \* Reliable change is clinical significance. (RC>+/-1.96)

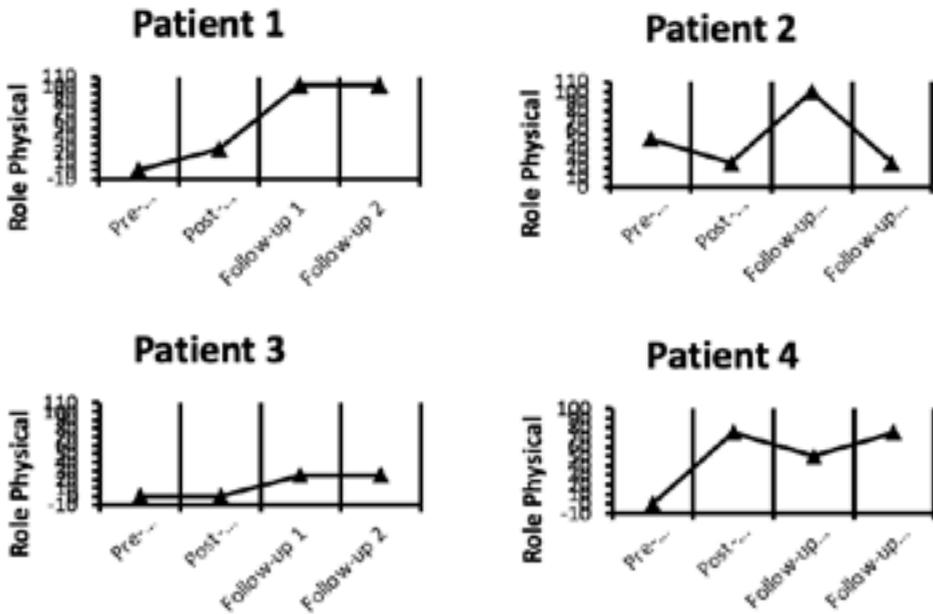
**Figure 1.** ABC Scale scores of the people according to their treatment periods



**Figure 2.** SF-36, Physical Functioning (PF) score



**Figure 3.** SF-36, Role Physical (RP) score



### Discussion

In this study, Basic BAT was effective in patients who developed WKS after the hunger strike. While the ABC scores of patients with WKS increased in post-treatment and follow-up periods, there was an improvement in the physical functioning and role physical scores of the SF-36 subscales. The changes were reliable and over time in the ABC were found to be positive in terms of people's improved balance confidence. Individuals continued their physical development after the Basic BAT application (Figures 1, 2 and 3). The positive effect of follow-up periods supported permanent results in terms of balance, coordination and motor skills in these patients.

One of the most severe symptoms of WKS is cerebellar ataxia. Cerebellar ataxia can cause postural instability, walking difficulties

and falling due to the inability to protect the centre of gravity in the balance line during activity (Jacobi et al., 2015; Stolze et al., 2002). It shows that in people with degenerative cerebellar ataxia, falls occur very often, and these falls lead to injury or fear of falling. Fear of falling can further impair balance control. Most of the falls due to ataxia are classified as intrinsic and centre-of-mass falls, and the main reason for most of these falls is disturbance of balance (van de Warrenburg et al., 2005). Another reason for the underlying main causes of postural instability in ataxia seems to be the "locking" of the knees compensated by reducing the interaction between the body connections (Bakker et al., 2006). With Basic BAT, very little flexion of the knee joints, increasing pelvis and trunk movement (opening/closing coordination) and providing alignment

of the body segments in the balance line are all important in the fall prevention strategy. The awareness of how to keep the body centre of the person in the balance line has increased, so balance and self-confidence may be improved. The patients with WKS stated that they walked by focusing on the balance line and that they were able to undertake more daily housework. Therefore, physiotherapy of the people with WKS should aim to correct gait abnormalities as well as to increase postural stability. One of the aims of physiotherapy in ataxia is to develop functional movements that improve the quality of life by increasing the independence of the patient while performing daily activities (Armutlu, 2010). It has been stated that intense continuous coordinative exercises improve coordination and dynamic balance in people with cerebellar ataxia, thus achieving personally meaningful goals in daily activities (Ilg et al., 2010; Ilg et al., 2009). In addition to body alignment and postural stability, we also focused on exercises that improve multi-joint coordination (opening / closing, turning and counter-rotation in the trunk) which are important for balance. Therapeutically, it is critical to be on the move, explore, experience, integrate and provide feedback on one's own movement coordination, and to gain more functional movement, strengthen their self and prepare for daily life (Liv Helvik Skjaerven et al., 2010). People with ataxia have been shown to have significant static and dynamic imbalance, which can directly affect their self-care, transfers and locomotion functions (Aizawa et al., 2013). It can lead to a significant decrease in daily life activities and social participation and can increase the dependency of people (Santos et al., 2018). Basic BAT strengthens the individual's "body ego" and increases confidence in one's body (A. L. Gyllensten et al., 2019). Although no qualitative assessment was made, one of the participants

mentioned an important development in our discussion following the group work. When she used a vacuum cleaner with oblique weight transfer movements that were learned from Basic BAT exercises, she moved "more comfortably without hurting her body and did not over-tighten her hands". This improvement in physical functioning and role physical subdomains may show that Basic BAT is effective as a physiotherapy method in the treatment of cerebellar findings like posture disorders and incoordination in people with WKS.

According to the results of this study, the patients with WKS showed positive developments nearly all subdomains of SF-36, if not significant. The people with WKS whose quality of life decreases due to fatigue, pain, impaired balance and fear of falling and whose are unable to carry out daily life activities, experience great deficits in their life in physical, psychological and social dimensions (Oudman & Wijnia, 2014). This may have a positive effect on increasing the mental concentration of the person, noticing and connecting with his body. With the continuation of the body alignment, there will be no excessive muscle tone; keeping the body in the balance line while walking will avoid excessive sway and therefore fatigue will not occur. In studies conducted, it is stated that fatigue decreases after Basic BAT and people feel more lively and comfortable (A. Gyllensten, L. et al., 2019). Overall, they were more active, and they lived a more stable life (Blaauwendraat et al., 2017).

The improvement after Basic BAT also affected the social lives of people with WKS. The fact that physical achievements resulted in independent movement increased social activity and enabled patients to better access society. Similarly, the restriction of daily activities seen in neurological patients affects social life negatively. On the other hand, Basic BAT interven-

tions in these patient groups enable people to take a more active role in daily life. The feedback we received during our group therapy is important to evaluate the healing process with Basic BAT. In addition, with the continued positive effects in the post-intervention period, the Basic BAT appears to positively affect the health of patients in the long-term.

### Limitations and strengths

The study had several limitations. In a study with a larger number of study participants, more meaningful results could be seen. Nevertheless, the design made it possible to study in-depth the effect of therapy in four chronic neurological cases. When the results of the study are examined, it is seen that it is close to the level of significance. In addition, according to participants' reflections on their experiences, all presented remarkable improvements in different daily activities. Another limitation is that the long-term nature of therapy causes many people not to participate. In addition, socio-economic conditions may make it difficult to continue therapy. If these patients with WKS can be reached with better opportunities, it can be clearly demonstrated that the Basic BAT is effective. We think that this study will be pioneering for future studies.

### Conclusion

As a result, the study shows that awareness of postural control with the Basic BAT in people with WKS will delay and limit physical deterioration, leading to loss of disability and independence in performing in walking and activities of daily living. This will lead to a wider accumulation of knowledge on sensory-motor rehabilitation and the improvements in the quality of life of patients. Basic BAT can provide a new perspective for the rehabilitation of people with WKS, however high-quality studies and evidence are needed to support

the intervention used.

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