The structured music therapy technique as way to improve psychosocial functioning of adults with phenylketonuria

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ABSTRACT

Aim: There is an evident relationship between the beneficial psychosocial aspects of music therapy and positive health effects in participants, both in the mental sphere and social health, which allows admitting that the level of appearance of psychosocial risk in individuals with phenylketonuria can decrease in the area of public health, thus affecting positively the quality of their functioning in the community on an everyday basis. Within the framework of the therapy the author examined whether the structured music therapy technique has a positive effect on psychosocial functioning of adults with phenylketonuria on an everyday basis in Poland. Materials and Methods: As part of long-term research the author introduced his own model of structured therapy for adults with phenylketonuria based on a number of elements, including: controlled expressiveness according to H.C. Traue (1998); interdisciplinarity; the phasicity of therapy according to R.J. Lueger (1995); the complexity of the specificity of factors connected with barriers of functioning of the disabled in the daily life; inclusion of family in the therapy; taking into account of the advantages of participants’ functioning in the therapy. The findings were obtained by means of participant observation in a group of 72 individuals aged 45–55 observed for eight years. Results and Conclusions: The overall clinical impression convinced the author to ascertain that the levels of improvement in the area of interpersonal communication, relations and self-assessment ranged from minimal to moderate for different participants of the therapy. The least improvement was obtained by patients with more intense distrust, frequent or constant thoughts connected with traumatic situations, experienced on a particular day, and those patients who showed aggressive behavior instead of communicating their stress verbally. A few patients in the group revealed development in a more adult style in the preferences of their independent roles towards their parents or partners. Some of them gained more trust, and several of them improved their ability to express themselves with a smaller intensity. Consequently, they became more accepted socially. The ascertainment is discussed in the light of the model of disability of individuals with a deeper intellectual disability and practical implications are suggested. Implications for rehabilitation are as follows. Firstly, the author ascertained positive health consequences in participants, in the sphere of both mental and social health due to their participation in music therapy sessions conducted with the structured technique. Secondly, in the face of strong emotional responses towards the leaders, it seems that the key factor in music therapy sessions is selecting patients and therapists with regard to their personality styles and their preferred working techniques. Thirdly, specialists working with individuals with intellectual disability must acknowledge the meaning of social support for physically disabled individuals and their families. Furthermore, therapists should focus their effort on providing assistance in experiencing and observing by participants their disturbed
perception and primitive defense mechanisms in a sufficiently changed quantity so that they can systematically improve their abilities in order to modify and neutralize their extremely negative reactions on an everyday basis. Additionally, the social environment should accept the fact that, owing to regular participation in music therapy, the level of participants’ social functioning rises significantly, which translates into their acceptance and social adaptation. Last but not least, the social environment should accept the fact that intensification of problems in the sphere of emotional and social functioning was higher in those patients who participated in music therapy sessions irregularly.

**Keywords:** Intellectual disability, Music therapy, Phenylketonuria, Psychosocial functioning

**INTRODUCTION**

For many years, therapists worldwide have been debating over the aims and the effects of using structured psychotherapy. Mental healers and music therapists include both supporters and opponents of using such methods. The practice of working with patients with phenylketonuria through the structured music therapy technique in Poland is rather little known and it has arisen out of therapeutic interest and research which has focused on this challenging population of patients for the last several years.

Since 2010 the Foundation for Propagation of Artistic Culture of the Disabled in Warsaw has been involved in various music therapy projects for adults with a deeper intellectual disability aiming at effective improvement of psychosocial functioning of adults with phenylketonuria. The structured music therapy technique was regarded as a highly promising model with positive results of personal resource support of adults with phenylketonuria. This paper presents a proposal of a therapy model for psychosocial stimulation of adults with phenylketonuria, a chronic somatic disease, afflicted with mental disability in a moderate degree. This model was designed as part of a project for psychosocial stimulation of patients with intellectual disability (2010–2014), participating in music therapy sessions at the above mentioned Foundation in Warsaw, supported by The National Fund for Rehabilitation of the Disabled (PFRON).

**PHENYLKETONURIA: A genetically determined metabolic block**

Congenital metabolic diseases are metabolism disorders caused by pathological genetic information. They result from a genetically determined deficiency of an enzyme activity, called a metabolic block or a congenital enzymopathy. One of the most frequent enzymopathy is associated with phenylalanine hydroxylase (PAH), which catalyzes the reaction of phenylalanine hydroxylation to tyrosine in the liver. Tetrahydrobiopterin is a cofactor in this reaction. A lowered PAH activity or lack of its activity leads to an increase in the concentration of phenylalanine and a growth of the concentration of phenylalanine metabolites, mainly phenylpyruvate and phenylacetate, in blood. As stressed by M. Walczak, classical phenylketonuria (hyperphenylalaninemia type 1) is caused by a congenital shortage of phenylalanine hydroxylase, the enzyme catalyzing transition of phenylalanine into tyrosine. Phenylalanine (Phe) is an exogenous amino acid, participating in protein synthesis. The excess of phenylalanine, as admitted by E.R. Behrman, is transaminated to phenylpyruvate acid or decarboxylated to phenylethylamine. These and other metabolites arising from them, disturb normal metabolism, involving anomalies in tyrosine and tryptophan metabolism, and cause brain damage [1, 2]. These compounds are toxic for the brain and cause anomalies in formation of myelin sheath in axons of the central nervous system, leading to deep mental disability [3, 4]. Recent scientific research confirms that phenylketonuria treatment still requires multilateral improvement. Numerous problems worth indicating include, firstly, the fact that, as indicated by reports, a certain group of examined individuals, even in the case of introducing a proper diet very early, do not attain a proper intelligence quotient (IQ). Secondly, those individuals have difficulties in learning as well as psychological and emotional problems, revealing especially during puberty.

**The effect of phenylketonuria on the intellectual development**

The scientific discourse concerning the effect of chronic somatic diseases on the development and functioning of...
the human nervous system is becoming controversial. Certain participants of the discourse maintain that the human nervous system is especially susceptible to any type of damage due to its specific immaturity. Other participants claim that the plasticity of the developing nervous system, especially in young individuals, allows using compensation mechanisms and adopting disturbed functions through its other areas. However, as claimed by M.E. Farmer (1994), W. Pilecka (2002), when, due to certain reasons, the central nervous centre becomes damaged, especially in the first years of a human’s life, it can result in a decrease in the general level of intelligence. Also, the revealed disadvantageous changes in cognitive functioning can frequently take a subtle form and avoid clinical or neurological diagnosis, however, they can affect the quality of an individual’s life through disruptions in memory, comprehension or a strong mood fluctuation [5, 6]. The moment the early phenylketonuria diagnosis scheme was introduced, research concerning the intellectual development of patients with phenylketonuria started to play an essential and positive role in designing a strategy and conducting a therapy [7]. In order to recognize the intellectual development of individuals with phenylketonuria properly, first of all, intelligence tests are used, e.g. The Wechsler Intelligence Scale for Children-Revised (WISC-R), which consists of the Verbal Scale, the Wordless Scale and the Full Scale [8]. According to P. Burgard, F. Schmidt, A. Rupp, W. Schneider, H.J. Bremer, the general population of children with phenylketonuria reveals differences between the intelligence quotient in healthy and ill children [9]. According to J. Weglage and his co-operators, an average level 2 in patients with phenylketonuria is 93.6 [10]. According to M.A. Vilaseca, N. Lambruschini, L. Gómez-López, A. Gutiérrez, E. Fusté, R. Artuch, J. Campistol, however, it appears that the findings of the research into intelligence correlate with the degree of maintaining a proper diet in ill individuals at every age [11].

Why music therapy?
Music therapy in activities for adults is used in rehabilitation, medicine and widely understood therapeutic work [12–19]. It seems to be an ideal form of psychotherapy especially when a non-verbal contact with patients is required. A significant percentage of adults with phenylketonuria reveal lingual difficulties of different origin and problems in establishing direct verbal contact. Those individuals encounter definitely more difficulties in the daily life than their healthy contemporaries [20]. Such a state leads to different problems concerning achievement of the intended objectives during performed tasks, a decrease in assessment of one’s own abilities and talents, extreme reduction of motivation for achievements [21]. Also, those individuals have difficulties in expressing their emotions, and when they reveal them, they are typically characterized with extreme behavior and attitudes. It is worth mentioning that most patients with phenylketonuria express a positive attitude towards establishing an active contact with music. Since methods proposed in music therapy offer a wide range of possibilities for motivating those patients, also in the form of amusement and tasks, during music reproduction, e.g. singing, applause, stamping their feet, playing a percussion instrument, music production, e.g. improvisations, interactive playing, or music reception, e.g. listening to music, relaxation, visualization, their utilization in the daily therapeutic work seems to be very justified. Besides, music therapy can be used both in a group and individually, both actively and receptively [20, 22, 23]. Also, the place for music therapy meetings does not need to meet strictly laboratory conditions. Music therapy in reference to adults with phenylketonuria with a low intelligence quotient can be treated as a form of art therapy and an excellent supplement of treatment through structured influence regarding stimulation, education or pathogenic biological, social or pathological factors [24–27].

The structured therapy (the script therapy)
The structured therapy is based on a model possible to be used in all patients, contrary to the individual approach. It is assumed here that script therapy for adults with phenylketonuria, with a considerably lowered level of intellectual development is based both on the foundations of both behavioral and humanistic psychology, psychoanalysis and elements of therapy through activity, i.e. musical tasks. Its music therapy treatment idea is based on the bio-psychosocial model designed by G.L. Engel (1977), and on resources and therapeutic techniques thoroughly checked in psychology and psychotherapy [28]. This model requires that recommendations included in the therapy scheme should be strictly followed. Therefore, the idea of music therapy is intended both for children with phenylketonuria and for adult patients with a lowered level of intellectual development.

A model of therapy structured towards adults with phenylketonuria
The model of music therapy conducted in Warsaw takes into account a range of elements, including: controlled expressiveness according to H.C. Traue (1998); interdisciplinarity; therapy phasicity according to R.J. Lueger (1995); the complexity of the specificity of factors connected with barriers of patients’ functioning in their daily lives; inclusion of their families in the therapy; taking into account the strong points of patients’ functioning in the therapy [20, 24, 29, 30].
Theoretical assumptions

The structured therapy for individuals with phenylketonuria was oriented interdisciplinarily as a modern therapeutic idea proposed in psychotherapy nowadays. It was designed on the basis of investigations and experiences of physicians, psychologists and music therapists, who designed an interdisciplinary model of treatment referring to music therapy. The theoretical basis was the Heidelberg model of treatment for adults with chronic pain, which was later modified, supplemented and transferred to the therapy for adults with phenylketonuria, taking into consideration their specificity, the understated level of their intellectual development and their individual needs [20, 29, 31]. The research team led by T.K. Hillecke made an attempt to analyze the concept by H.C. Traue in the therapeutic context and separated four areas which in this instance were regarded as essential for patients with phenylketonuria. Due to the specificity of phenylketonuria, the favored aspects, remaining in a strict correlation, were referred in this instance to: 1) limitations in reception of one’s self-image; 2) limitations in the interpersonal area of social contacts; 3) strengthening of musical activity; 4) indicating positive closer objectives. Limitations in reception of one’s self-image can be manifested in patients’ focusing continuously on their weaknesses, causing a feeling of being “different”, or “worse”. Limitations in the interpersonal area of social contacts translates into changes in the approach to problem solving, to socially acceptable ways of establishing new relationships, to solving conflicts on an everyday basis. Individuals with phenylketonuria wish to be independent but at the same time their environment very much limits their attempts of independent activity and creativity. Moreover, those individuals usually have problems with recalling “positive memories”, which can lead to unwanted depression and fits of misbehavior (e.g. dematerialization of beloved objects). The model of the therapy also allows for the additional factor of musical flexibility, thanks to which patients are open to new possibilities of functioning on an everyday basis. This factor forced, as it were, activating several special music therapy techniques, e.g. the variability of music parameters in free improvisation; the association of sounds in an emitted color box, e.g. joy - red, calm - green. The theoretical basis of music therapy includes the continuation of additionally extended activities in the field of neurological music therapy (NMT), with special focus on the therapeutic effect in patients’ experiencing and feeling, their motor dysfunctions, their music perception and production and the influence of music on functional changes of the non-musical brain and behavioral functions [26, 32–34].

Course of the therapy

The group of the project participants included 15 men aged 45–55. The music therapy work was based on a phasic model, taking into account certain psychical and behavioral changes in patients: phase 1 – radiation, involving noticeable changes in one’s mood and self-confidence; phase 2 – stimulation, involving noticeable changes in the intensity of one’s own activity, improvement in motivation regarding social functioning; phase 3, involving improvement in “general functioning”, noticeable changes as regards extending one’s independence in coping with situations of the daily life. Consequently, during the three-phase course of music therapy, the therapist’s effort is aimed at improving patients’ general mood, reducing the frequency of their fits of anger and their reluctance towards activity, reducing their states of extreme emotional lability, their unexpected overexertion and frustration, and finally improving their general functioning in task situations on an everyday basis. During the activities all the phases were therapeutically performed and analyzed in compliance with the objectives of music therapy.

Objective of the therapy

The main objective of the therapy was to reduce the frequency and the intensity of fits of anger, reduce reluctance towards activity and the states of extreme emotional lability, limit the overuse of physical power causing states of frustration and dissatisfaction. Moreover, due to the occurrence of an understated level of patients’ intellectual development and consequently a limited degree of comprehension of most musical tasks, the therapy was based primarily on the technique of playing percussion instruments. It should improve the range of exercises and stimulate motor patterns functionally in motor therapy, owing to interaction in cognition, feeling and motor dysfunctions; perception and production of music and its influence on functional changes. While playing the instruments selected in specific configurations, the participants are supposed to improve the scope of their movement, endurance, muscular power, co-ordination in lower and upper extremities, posture control, agility, dexterity, grip, body mobility, perception and feeling. Also, the assumptions did not omit the necessity to correct patients’ attention and perception. Therefore, a special focus is on the necessity to improve patients’ orientation with relation to themselves, other individuals, place and time, taking into account their attention and reactions caused in them by music (Music Sensors Orientation Training).

The music therapy idea

Every meeting with a music therapist is accompanied with elements creating the uniformity of influences, consisting in the consequence of maintaining repetitive activities and at the same time strengthening the sense of security, harmony, emotional stabilization and psychical relaxation. When defining the music therapy idea, the
focus was on the following needs: to define the objectives of individual phases of the therapy; to set the objectives of the therapy, according to the main aims; to define specific music therapy factors; to choose suitable music therapy techniques (Table 1).

Phase 1 of the therapy, i.e. radiation, focused mainly on building a relationship between the therapist and the patient through well-known rituals, contact games, musical tasks causing relaxation with elements of verbal induction as psychical and physical relaxation techniques, escape from daily worries, stimulation of imagination. Another objective was to create the atmosphere for stabilization of good mood while using a variety of musical parameters to improve the possibility of strengthening the feeling of self-confidence in patients, e.g. musical accompaniment to movement, vibroacoustic stimulation, the technique of sound association based on emitted colors.

Phase 2 of the therapy, i.e. stimulation, was concentrated mainly on revealing changes concerning the intensity of motivation for activating various forms of patients’ own activity, e.g. spontaneity, an image of feelings, a portrait of a person. Another objective was to improve the level of motivation as regards patients’ social functioning by indicating a possibility of different solutions as well as exploring new aspects of survival, observation, experiencing. In its next step, the therapy will bear fruit with a positive change of patients’ attitudes towards the environment together with a possibility to elaborate changes in behavior on an everyday basis. In this phase, an important issue is to learn musical freedom and flexibility, which significantly improves the scope of patients’ movement, their endurance, muscular power, co-ordination in the area of lower and upper extremities, posture control, agility, dexterity, grip, body mobility, perception and feeling.

The last phase of the therapy, Phase 3, was focused on improving and stabilizing the already learned attitudes, techniques, experiences and introducing them into the extended resource of coping with life independently on an everyday basis. For this purpose, the technique of Musical Self-Portrait was used. In tasks aimed at improving independence patients have a possibility to “work out” their own attitudes in improvisation in a role play. Here, special focus is on such attitudes that eliminate aggressive behavior, reduce anger and support patients’ coping with difficult situations and emotions. This phase ends with saying goodbye to the therapist, although it does not exclude an opportunity to participate in another session of the entire cycle of music therapy meetings (Table 1).

Additionally, the cycle of music therapy includes meetings with patients’ parents and doctors who take

<table>
<thead>
<tr>
<th>Aim in phases of the therapy</th>
<th>Detailed aim</th>
<th>Specific factors in music therapy</th>
<th>Music therapy techniques</th>
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<tr>
<td><strong>Phase 1: to improve the level of subjective mood and self-confidence (on average 5 therapeutic hours)</strong></td>
<td>Constructing a strategy for therapeutic relationship</td>
<td>Learning rituals in therapy and solidifying them; acceptance of the established model of work during music therapy sessions</td>
<td>Playing an instrument - “contact” playing; musical tasks causing relaxation with elements of verbal induction</td>
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<td>Stabilization of good mood</td>
<td>Stimulation of internal resources by listening to music and playing favorite music pieces</td>
<td>The receptive technique of sound association based on emitted colors</td>
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<td>Training towards strengthening one’s self-confidence</td>
<td>Musical reflection and fulfillment of the achieved success in musical work</td>
<td>Musical accompaniment to movement, vibroacoustic stimulation, improvisation entitled “My greatest dream”</td>
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<td><strong>Phase 2: to improve the intensity of one’s activity and motivation in social functioning (on average 6 therapeutic hours)</strong></td>
<td>Working on the intensity of task performance</td>
<td>Stimulation for tasks by providing instructions with the musical form, using music for experiencing success in task performance</td>
<td>Improvisation according to one’s favorite patterns of sound and rhythm</td>
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<td>Working to improve motivation in the area of social functioning</td>
<td>Stimulation using music therapy and imagination; constructing alternatives; musical freedom and flexibility</td>
<td>A variety of musical parameters in free improvisation (rituals)</td>
</tr>
<tr>
<td><strong>Phase 3: to improve the area of “general functioning” and changes as regards extending manners of independent resourcefulness (on average 8 therapeutic hours)</strong></td>
<td>Testing new types of behavior and experiences</td>
<td>Practicing new forms of interaction through non-verbal musical communication</td>
<td>Musical improvisation with role play; patients’ own compositions including the light technique</td>
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<td>Generalization in the area of one’s independence in increasing one’s ways of resourcefulness</td>
<td>Stabilization of the achieved aims - improvement; saying good bye</td>
<td>My Musical Self-Portrait – evolution of types of behavior regarding one’s resourcefulness</td>
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**Source:** The author’s own study
care of them. The idea of those meetings is to regularly exchange experience and hold consultations in order to standardize the influence of patients’ contact with music in their family homes and in the cycle of pharmacological therapy.

The aim of the suggested music therapy for adults with phenylketonuria with a lowered level of intellectual development is not only to make therapists interested in active psychosocial stimulation of their patients, although this is a very important goal. The general clinical impression convinced that the levels of improvement of patients’ interpersonal communication, relationships and self-assessment ranged from minimal to moderate for individual participants of the therapy. The least improvement was obtained by patients with the most intensified distrust, frequent or permanent thoughts connected with traumatic situations experienced on a particular day and those patients who showed aggressive behavior, instead of communicating their stress verbally here and now. A few patients in the group revealed development of a more adult style in their preferences of independent roles towards their parents or partners. Some patients obtained more self-confidence and several patients improved their ability to express themselves with a smaller intensity. Consequently, they became more accepted socially. Such results convince that music therapy tasks should be aimed primarily at helping patients to experience and observe their disturbed perceptions and primitive escape mechanisms in a sufficiently changed quantity so that they can systematically improve their own ego abilities in order to modify and neutralize their extremely negative reactions on an everyday basis. It is widely accepted that in the continuity of systematically organized musical influences, the emotional and social development training is easily implemented. It is in this group that the risk of the occurrence of difficulties in psychosocial adaptation seems very high, and by participation in music sessions the following issues can be considerably improved: the quality of emotional functioning and one’s own self-assessment; the level of social adjustment and the maturity of one’s need to maintain contacts with other people; the ability to experience success, recognition and acceptance of one’s own achievements. Moreover, states of nervous and emotional balance can be significantly improved; patients with generalized symptoms of hyperactivity and inhibition can definitely easier overcome problems in their adaptation to therapists’ requirements, expectations and norms of the community. During their participation in music therapy, numerous patients showed a considerable degree of improvement in focusing their attention. As stressed by researchers into the problem, in this group of patients numerous individuals are afflicted with hyperactivity, states of anxiety or an inflated level of fear [35]. During the analysis of the author’s findings concerning the participants of music therapy, convincing data were obtained showing that under the influence of regular participation in activities their level of social functioning rose considerably. Also, the obtained data confirm that there is a relationship between the duration of music therapy and the intensification of observed problems as regards functioning and the emotional state of participating patients. Longer periods of participation in music therapy meetings correlate with a smaller intensification of difficulties on an everyday basis, an increase in the level of satisfaction with life, bigger openness to others, a decrease in the level of physical complaints. Moreover, on the basis of information obtained during the observation of music therapy participants, it was possible to ascertain that the intensification of problems in the sphere of emotional and social functioning was bigger in those patients who participated in music therapy meetings on an irregular basis. It seems that in the strategy of influence by music it is extremely essential to take into account the fulfillment of the need to maintain permanent contact of therapists with parents or their relatives in order to increase the continuity of social support of the discussed group of patients.

CONCLUSION

Summing up, it can be confirmed that there is serious scientific evidence showing a clear relationship between the psychosocial benefits of music therapy and positive health consequences in patients, both in the sphere of mental and social health, which provides the basis to accept that the level of appearance of psychosocial risk in individuals with phenylketonuria will be decreasing in the area of public health, affecting positively the improvement in the quality of their functioning in the community on an everyday basis.

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Author Contributions
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