Values of Artistic Activity in Social Development of Individuals with Johanson-Blizzard Syndrome

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Abstract: This paper aims at examining the relationship between the psychosocial conditions of artistic activity through dance and its effect on women with Johanson-Blizzard syndrome (JBS), concerning their mental and social health, their social and emotional development in the area of public health as well as the quality of their functioning in their communities. The dance therapy exercises were based on a choreographic system invented by the author as a profile of research into social and emotional development of women with Johanson-Blizzard syndrome. On the basis of participating observation, the author gathered and discussed the results of achievements of three women aged 20-25 participating in dance activities for five years.

The findings proved that the level of the risk of delay in the process of social and emotional development in individuals with Johanson-Blizzard syndrome could considerably decrease in the area of public health, positively influencing the improvement of the quality of independent functioning of women in their communities. For five years the described women developed an improvement in the areas of interpersonal communication, relationships and their self-assessment. Also, respondents developed a more adult style in their preference of independent roles towards their parents and their partner in one case.

Keywords: Johanson-Blizzard syndrome, dance therapy, psychosocial functioning, artistic activity, emotional and social development

Introduction

Individuals afflicted with a complex of congenital anomalies called Johanson-Blizzard syndrome (JBS), are characterized with a rare autosomal recessive state, involving particularly pancreatic exocrine insufficiency, oligodontia, growth retardation, hearing loss, mental impairment, skull defects, hypothyreosis, a congenital heart defect and others, e.g. anus anesthesia (Alpay, Gül, Lenk, & Ogur, 2000; Johanson & Blizzard, 1971; Kulkarni, Shetty, Kallambella, & Kulkarni, 2004; Mcheik, Hendiri, Vabres, Berthier, Cardona, Bonneau & Levard, 2002; Zenker, Mayerle, Reis, & Lerch, 2006). Individuals described in this paper reveal an underdevelopment of the central part of the face, though the spectrum of potential functions and physical symptoms associated with JBS have an individual nature and have a wide and diverse dimension. This study focuses on three cases of women aged 20-25 who, within a period of five years, as a result of active participation in organized artistic dance activity, obtained an unexpectedly high level of functioning in their independent lives on an everyday basis. The described women revealed substantial differences in their appearance, differences in the level of their social functioning, the status of their origin, the case history, the type of family complications, yet all the cases confirmed the assumptions that all physical defects, such as exocrine pancreatic insufficiency, intellectual disability, limitations caused by heart defects, anomalies regarding sight and touch, internal and external complications in disorders and deformations of the body, do not eliminate their social functioning and the final shape of the course of the social and emotional development of individuals with Johanson-Blizzard syndrome (Cheung, Thomson, Buncic, Héon & Levin, 2009; Elting, Kariminejad, de Sonnaville, Ottenkamp, Bauhuber, Bozorgmehr, Zenker, & Cobben, 2008; Zenker, Mayerle, Lerch, Tagariello, Zerres, Durie, Beier, Hülskamp, Guzman, Rehder et al., 2005; Zenker, Mayerle, Reis, & Lerch, 2006). The women involved in this study come from Warsaw, Poland, they are from Jewish families and their parents are related in the first degree. Earlier their parents lived in Kazakhstan (one family), Ukraine (one family), Israel (one family). The women revealed typical features of the disease, i.e.: pancreatic hypofunction, congenital hypothyroidism, sensory deafness, short stature, typical JBS facial features, lack of permanent dentition (large orthodontic anomalies), atrial septal defect and heart failure in one case (Alpay, Gül, Lenk & Ogur, 2000; Gershoni-Baruch, Lerner, Braun, Katzir, Iancu & Benderly, 1990; Sandhu & Brueton, 1989). Intellectual disability was found in all the women. Also, it was ascertained that the respondents’ hearing was psychomotoric development were correct, which clearly confirmed the conviction that they have a relatively gentle phenotype.

Why artistic activity through dance?

Studying the specificity of motoric activity of individuals with Johanson-Blizzard syndrome is not an easy task because each individual body language user has a unique module of his or her personal motoric experiences (Williams, 2004). When including the group of women described here in dance classes, the class educators primarily bore in mind an attempt to isolate the participants’ body language from their individual manifestations, consequently separating what is social from what is individually caused or defined in connection with the possessed syndrome, and what is essential from what is accidental. The point was to allow dance class participants with JBS, according to their individual possibilities, to consider their body movements as signs or symbols of their emotional states currently expressed as their subjective feelings. That symbolism shown in the participants' gestures, poses and motoric sequences was supposed to model the forms of their motoric activity while communicating their mood. It was supposed that the essence of the power was in the cognitive-sensory-motoric and aesthetic ability to create the body and transform the current and often disordered state of mood, e.g. emphasizing or denying a linguistic form of communication. Another point was to allow the motoric activity accompanying the participants' emotional sphere to stimulate or sublimate the palette of their feelings conveniently during exercises. In this case dance was supposed to be a form of escape from all restrictions and limitations connected with their disease. When moving in time and space, the dancers' bodies allowed kinesthetic communication (Anderson, 1974). Empathy between the dancer and the recipient, revealed in the dance, allowed transfer of information, direct co-experience and specific somatic-muscular reception. Apart from the kinesthetic way, dancing permitted transferring meanings via additional channels, such as visual, sonic, tactile and aromatic channels (Hanna, 1987). Therefore, dance participants were offered five transmission channels allowing information transfer. Therefore, as a result, artistic activity classes through dance, in reference to adult females with JBS with a low intelligence quotient appeared to be a definitely suitable and individually available form of art therapy and an excellent form of supplementing the treatment process through properly structured influence concerning stimulation, education as well as pathogenetical, biological, pathological and social factors (Cheung, Thomson, Buncic, Heon, Levin, 2009; Hillecke, 2006; Lueger, 1995).

A Model of artistic activity through dance for individuals with JBS

The model of artistic activity through dance, designed and used in Warsaw, involved a number of elements as follows: controlled expressiveness according to Traue (1998); interdisciplinarity; therapy phasicity according to Lueger (1995); the complexity of the specificity of factors connected with barriers of functioning of individuals with JBS in their daily lives; inclusion of participants' families in the therapy; considering strong points in functioning of dance therapy participants, social and emotional development, socializing stimulation (Farmer, 1994; Lueger, 1995; Traue, 1998). Apart from the described women also a group of men with intellectual disability participated in the dance group. All the dance classes participants were of age and had parents or one family member. The stimulation classes were held once a week and lasted three hours. In special cases the participants met twice a week, mostly before public presentations of their skills.

Method

The course of dance therapy for participants with JBS. The author used his method of motoric activation by dance. Moreover, the author took into account the monographic method and the qualitative method: observation, interview, documentation analysis, valuation.
The procedure included three phases. These are detailed as follows:

Phase 1

1. Observing and noting the basic difficulties and limitations in participants' movement in dance;
2. Formulating a conception of motoric stimulation-through-dance activities; and
3. Analytic and experimental confirmation of key functions of the introduced motoric stimulation-through-dance activities.

Phase 2

1. Verifying new components of motoric stimulation-through-dance activities in reference to individual dancers' cases;

2. Verifying new components of motoric stimulation-through-dance activities in reference to a group of dancers;
3. Building a model of a set of motoric stimulation-through-dance activities aimed at therapeutic development (referring to individuals); and
4. Building a model of a set of motoric stimulation-through-dance activities aimed at therapeutic development (referring to groups).

Phase 3

1. Implementing the model of motoric stimulation-through-dance activities in a group;
2. Verifying therapeutic developmental activities through their particular applications;
3. Accepting the final version of the method for motoric development through dance.

Individuals invited to participate in artistic activity classes through dance were three women aged 20-25 in 2012. Dance therapy was based on a phasic model considering certain psychological and behavioral changes in participants. The dance therapy model consisted of 3 phases: phase 1 - radiation, involving noticeable changes in participants' mood and self-confidence; phase 2 - stimulation, involving noticeable changes regarding the intensity of one's activity, improvement of motivation regarding social functioning; phase 3 - improvement in the area of "general functioning”, perceptible changes concerning extensions of ways to cope independently with everyday situations. Consequently, during the three-phase course of dance therapy, the educator/therapists’ effort was aimed at improving the participants' general mood as well as reducing the frequency of fits of anger, reluctance towards activity, the states of extreme emotional lability, unexpected excessive effort, states of frustration and finally improving the participants' general functioning in task situations on an everyday basis. All the phases of pedagogic conduct during the activities were thoroughly worked out, analyzed and executed in compliance with the set aim of dance therapy, i.e. optimization of the social and emotional development of the respondents with JBS.

The social and emotional development of individuals with JBS

The social and emotional development of individuals with Johanson-Blizzard syndrome, if properly supported, creates an extremely important foundation of their socially expected functioning during all their lives. Their participation in artistic activity through dance allowed creating a splendid opportunity to provide those participants systematically with competences which allow effective and satisfactory adaptation in the environment, both now and in the future. Furthermore, properly provided care and artistic education in implementation of health and intervention schemes during participation in artistic stimulation, allowed supporting the development of skills essential for educational and social success of all dancers. Planning influences aimed at optimizing social and emotional development, including its compensation in the described group of participants, requires recognizing weak and strong points of their functioning as regards their self-reliance, persistence, curiosity, skills, resourcefulness and talents. In order to achieve it, the author used the knowledge concerning the course and the correctness of the social and emotional development of women with Johanson-Blizzard syndrome, and on this basis, he tried to select suitable tools allowing monitoring constantly their emotional and social development through dance and other motoric and musical exercises in the group of thirty individuals. As stressed by R. Thompson “[...] social relations create a context which is the most essential for developing the skill of coping with emotions and the effectiveness of those skills depends significantly on reaction of social partners and challenges of the social environment" [...] (Thompson, 1994).

For the needs of the discussed issues, the validity of the description of observable types of behavior of individuals with Johanson-Blizzard syndrome, it was assumed that social and emotional competences provide an ability to understand and control one's feelings and behavior, understand other individuals' feelings and establish harmonious and friendly relationships and relations with other all other participants of artistic activity. The model used for recognizing and designing a preventive and interventionist scheme for the needs of stimulation with dance considered five categories of social and emotional competences which revealed the most frequent difficulties among the described cases, i.e.: self-awareness, social consciousness, responsible decision making, controlling one's behavior and controlling relations with other individuals in the group (Zins, Bloodworth, Weissberg, & Walberg 2004). In this scope, the author gradually increased the number of situations which allowed eliminating effectively any emerging difficulties and improving earlier taught techniques of coping on an everyday basis.

As regards women with JBS, it was assumed already at the start of collaboration with educators that those individuals could feel discomfort in establishing contacts with their peers, regardless their register age and the degree of limitation caused by their disease. It was caused by the fact that those individuals normally experienced a feeling of excessive occurrence of disadvantageous changes in their cognitive functioning. Those changes sometimes took a subtle form and did not give in to accurate clinical or neurological diagnosis. Consequently, however, those had a considerable negative impact on the quality of functioning of the discussed participants in their artistic stimulation through, e.g. disruptions of memory processes, understanding or a strong mood fluctuations, irritation and lack of self-confidence (Farmer, 1994). After introducing a proper scheme for recognizing potential psychomotoric abilities in the respondents, all the obtained information played an essential and positive role in designing a strategy of methodical conduct, and allowed using dance therapy effectively (Lanie, 2010).

Results

While diagnosing the women with JBS it was assumed that the previously mentioned competences and skills presented in Table 1 were developed in different degrees starting from their birth through subsequent stages of development and on the basis of gradually acquired and formed competences.

Table 1. Categories of Social and Emotional Competences Developed in Women with JBS (at the Elementary and the Advanced Stage of Dance Classes Scheme)

Category	Component competences	1st stage of participation	2nd stage of participation
Awareness	- identification and recognizing one's emotions; - perception of oneself adequate to reality; - adequate recognition of one's features (strong	weak weak weak	correct correct correct

	and weak points);		
	- efficiency in achieving goals.	weak	good
Social awareness	- ability to take other individuals' points of view;	weak	correct
	- empathy;	weak	correct
	- acceptance of differences between people;	weak	weak
	- respect to others.	expected	correct
Responsible decision making	- a skill to analyze the situation in order to identify the most important problems;	weak	correct
	- problem solving skills;	weak	sufficient
	- ability to reflect over one's behavior;	weak	expected
	- ability to take responsibility.	weak	correct
Controlling one's behavior	- controlling one's impulses (restraining, modulating, socially accepted expression);	weak	good
	- internal motivation for activity;	weak	good
	- controlling one's behavior;	weak	sufficient
	- self-discipline;	weak	expected
	- ability to set aims and organizing one's activity.	weak	expected
Managing one's relations with others	- communication skills (transferring, receiving and interpreting information);	expected	good
	- ability to become involved emotionally and build relationships with other people;	weak	expected
	- negotiation skills;	expected	expected
	- ability to refuse in a socially acceptable way;	weak	expected
	- ability to solve conflicts with others;	weak	expected
	- ability to ask for help and offer help.	expected	good

Source: the author's study, based on Zins, Bloodworth, Weissberg and Walberg (2004). Rating equivalents: *weak* - a hardly perceptible level of participants' signs; *expected* - a level comparable with one's peers; *correct* - a level better than expected, though lower than sufficient; *sufficient* - a level higher than expected - signs have their own acquired elements; *good* - a level of one's acquired signs established above the expected level in reference to one's peers.

On the basis of the carried out survey with the women's parents it was ascertained that in each family the development of competences in a child was solved differently and with very varied results. The organization of stimulation by dance therapy in the described women with JBS involved primarily those categories of competences which in the educators' and parents' opinion were rated at a deficit level.

Table 2. Factors Which Support and Disrupt the Functioning of Women with JBS

Type of factors	Individual development (ontogenesis)	Family (a microsystem)	Local environment (an egzosystem)
Permanent risk factors	• chronic health problems • insufficient care and relations with parents in one's early life • intellectual retardation (intellectual defect)	• lack of support motivating for artistic activity • financial difficulties • the parents' psychological problems	• lack of understanding of the situation in the local environment • social acceptance for intolerance • social isolation • racism, exclusion
Temporary risk factors	• diseases and complications connected with the syndrome • difficult life situations • temporary failures	• difficulty in harmonizing one's professional career with taking care of one's child • separation or divorce • daily problems	• loss of social support • temporary conflict in providing health and social care
Permanent supporting factors	• easygoing personality • talents and inborn skills • good adaptation to a group • willingness to learn	• good matrimonial and family relations • parents' regular employment • a high level of child care in the dancing activity	• support from the local network • support from humanitarian organizations • good social services • permanence of dance activities

Temporary supporting factors	• taking pride in one's own dancing achievements • good relations with the dance instructor and volunteers	• positive results of care • organization of non-family care • support from one’s family	• social support from public benefit organizations • providing resources for medical therapy

Source: the author's own study based on Cicchetti, Toth and Maughan (2000).

The pedagogic and psychological focus was mainly on the women's particular abilities to establish relations with other people, e.g. smile or vocalization, and this was the basis for further gradual enlargement of chances for developing other social and emotional skills. However, this task did not appear to be easy because the emotional baggage connected with overcoming difficulties connected with daily activities involving health and hygiene, opposing constantly to attacks of pain and unexpected physical limitations of their bodies, comparatively large daily doses of medicines and obligatory supplementary therapies, often led to life apathy, low motivation and reluctance to overcome difficulties connected with dance and education. The two-stage participating observation during the women’s artistic activity took into account the level of factors supporting and disrupting their functioning at the first stage of collaboration, and then at the advanced stage (Table 2).

The observation was affected on the basis of the author's observation sheet for individuals with JBS. For this purpose, the ecological transactional model was used, which allowed proper understanding of the course and effects of the development of artistic activity in the participants. The author used a wide analysis of the context of the lives of women with JBS, examining a great number of external (interactional) factors, connected with the characteristics of the environment, and internal factors, connected with the profiles of individuals, whose interactions shape one's individual development (Cicchetti, Toth, & Maughan, 2000). Such a look at the described women, as developing individuals, functioning under certain conditions and subject to different influences, created conditions for the theoretical basis for diagnosing and designing adequate individual schemes to support the development and provide suitable specialist therapeutic assistance in individualized categories.

Summing up the obtained results of participation of individuals with JBS in artistic stimulation through dance for the period of five years, it can be confirmed that the obtained results were impressive. When comparing in Table 1, the results of Stage 1 (elementary) with Stage 2 (advanced), it can be noticed that the development of the scope of competences in all participants reached statistically a very positive result. A favorable improvement was observed almost in every competence category, and in some categories an unexpectedly high level was reached. What is more, young women showed a positive change of their attitudes towards their friends and colleagues together with a possibility to introduce constructive changes in their behavior on an everyday basis. Learning musical freedom and flexibility appeared to be an important factor which allowed individual participants to significantly improve the scope of movement, their endurance, muscular power, co-ordination of lower and upper extremities, their postural control, dexterity and grasp, body mobility, perception and feeling. Moreover, on the individual level, participants showed a higher level of general improvement and stabilization of learned behavior, techniques, experience and using it for extended self-reliability and resourcefulness in their lives on an everyday basis.

Discussion

When emphasizing the values of artistic activity through dance in the social and emotional development of individuals with JBS, it must be stressed that this form of art therapy can become an extremely essential element in their lives to complement the process of supplementary therapy and their adaptation to the social environment. It must be stressed that newly formed social competences of the described women with JBS and the freedom with which, under the influence of participation in artistic stimulation, they were able to establish relations with their peers, does not remain in a distinct relationship with their inclination towards externalizational behavior, e.g. damaging objects, revealing signs of fury, falling into states of disappointment, transferring their aggression to objects of daily use. It appears that externalization seems to occur regardless of one's health condition and can be negatively connected with the ability to take social roles and cope with tasks associated with one's independent functioning in the community. Controlling one’s externalizational behavior seems to be strongly related to cognitive functioning, which could be evidently observed in this study. It must be admitted that developing the ability to focus participants' attention on dance for a longer period of time in the elementary phase was also a serious problem and was reflected in connection with other competences concerning the ability to control one's emotions and behavior. Therefore, it is no surprise that one can observe a correlation according to which the smaller the individual's ability to focus his or her attention, the higher the intensity of externalizational behavior. This problem was particularly stressed regarding therapeutic influences in artistic stimulation through dance.

The positive relationship of reaction to artistic activity as an innovation in the lives of women with JBS with the level of their socialization, i.e. with their social competences and freedom in establishing social relationships confirms the hypothesis that difficulties in social relations acquired during supplementary therapy and long-term pharmacotherapy are often a consequence of an inflated level of fear of new situations in life and types of behavior in the community. In this case, one's self-assessment tended to remain on a very low level with a downward trend towards the extremity. Owing to their participation in artistic stimulation, the described respondents strengthened their self-assessment and consolidated the level of their self-assurance and the feeling of their personal value.

It can be accepted that depriving young women with JBS with intellectual disability of any possibilities to participate in artistic stimulation can lead to extreme limitation of their chances for developing their independence in social roles in their adulthood. Such isolation will result in losing their chances for development in order to start their professional career and fulfill their plans to start their own families. Without being provided with medical and social support and care, those individuals have practically very limited possibilities to survive in the community. Since their fate and lives are, as it were, doomed to constant fight with a chronic disease and difficulties in becoming independent, doomed to a struggle for social adaptation and decent existence with permanent outside assistance, everything should be done so that they could participate in different forms of social stimulation. Due to this reason, it is worth implementing different forms of artistic stimulation for those individuals in order to successfully open the window on the outside world for them. As indicated by the results of the observations in artistic stimulation through dance, participants with JBS significantly improved the area of interpersonal communication and their relations and self-assessment reached an unexpectedly positive level, i.e. from 'weak' to 'good'.

Implications for rehabilitation

Summing up, on the basis of the findings of the study it is also worth indicating the following implications for rehabilitation:

- The study found positive health consequences in women resulting from their regular participation in dance therapy, both in psychophysical and social health;
- In the face of the revealed emotional reactions towards therapists in dance therapy, it seems crucial to select educators and therapists who carefully consider their personality styles and preferred techniques of artistic work;
- Specialists working with disabled individuals, including those with Johanson-Blizzard syndrome, must accept the significance of social support for this group and their families, especially as regards chronic diseases and psychophysical indispositions;
- Educators and therapists should focus their efforts on providing participants with assistance in experiencing and observing their disrupted perceptions in a sufficiently changed quantity so that they can systematically improve, modify and neutralize extremely negative reactions caused by chronic states of illness and anxiety;
- The social environment, including medical staff, should accept the fact that, influenced by regular participation in dance therapy, the level of independent social functioning of participants with Johanson-Blizzard syndrome increases considerably, which translates into the level of their being accepted in the community and reduction of stress associated with overcoming complaints connected with their disease;
- It must be accepted that that intensification of problems regarding the development of social and emotional functioning of women with Johanson-Blizzard syndrome has an upward trend together with irregularities of their participation in dance therapy sessions.

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