Dance Teaching for Hemophiliacs Patients from the Clinical Hospital of the State University of Campinas, Brazil: Description of an Experiment

Nathália Lisiê Pozzuto Borelli & Mariana Baruco Machado Andraus

Abstract

This paper presents the results of a dance classes project that aimed to generate and report physical improvements and upgrades for hemophilia patients. In addition, we sought to develop the self-knowledge of these patients, who are from the Blood Center of the State University of Campinas, through dance work focused on body awareness and the creation through the sensations and emotions of each one of them. Thus, we intended that such patients had greater awareness of their limitations and difficulties so that, alongside the exercises given in classes, they could find better ways to improve or even deal with them, accepting their bodies as how they were. Regarding the body exercises creation, they realized how important it is for each individual to have their own way of expressing themselves through body motions, without worrying about stereotypes that society generally expects them to possess, therefore generating greater confidence in themselves.

Keywords: Hemophilia; body awareness; creation; limits; therapy

The work described in this article was intended to systematize exercises based on concepts studied and worked in the classes of the graduation course of dance in the State University of Campinas, especially for the difficulties experienced for hemophiliac patients, trying to work body consciousness concepts and techniques, because we realized, living with them, that a deeper knowledge of the own body would benefit those people. According to Imbassaí, “The principle of the body consciousness is the attention with the sensations, dynamics, posture, tonus and body balance” (Imbassaí, 2008, p. 50), and it was in this direction that we initially started the work. We didn’t restrict ourselves, however, only to this guideline, since “body consciousness” is a broad concept and covered not only by the dance. Nowadays, physical education professionals and physiotherapists apply techniques like Pilates that, although originated in context of dance, exceeded obstacles and it has become a widely spread technique of body work, highly requested by lay audience and taught by professionals unrelated to the dance (Andraus, 2014, p. 80). We wanted something more: take the opportunity and to develop a more complete work of education for the dance, also, an aesthetics education.

1 Derivative article of completion course work of the first author, developed under the guidance of the second author, in the Licentiate Course of Dance at the State University of Campinas, in the year of 2014.
2 BA in Dance from State University of Campinas (Unicamp). Institutional adress: Institute of Arts, Department of Corporal Arts. 500 Pitágoras Street, Cidade Universitária Zeferino Vaz, 13083-854, Campinas-SP. E-mail: nat_unicamp@hotmail.com
3 Coordinator of the Post-graduation Program in Performing Arts and Professor of the Department of Body Arts of the University of Campinas. Post-Doctorate in Education from the Catholic University of Campinas (CAPES sponsorship). Doctor in Performing Arts from the State University of Campinas (Unicamp). Institucional adress: Institute of Arts, Department of Corporal Arts. 500 Pitágoras Street, Cidade Universitária Zeferino Vaz, 13083-854, Campinas-SP. E-mail: mari.baruco@gmail.com
4 We stress the use of the word “patient” in some article’s excerpts since to the work has been developed in a hospital institution, which users are thus identified. Throughout the article, however, this “patient” becomes “patient/student” and, at the end, we discuss the term patient in a concept of art-education who understands the person as a subject, owner of her own body, able to choose independently the way how she perform movements, provided that it is present a full consciousness of her own body and its possibilities.
Therefore, on the one hand, the work of body consciousness allowed the patients/students more attention about their pain, difficulties and limits, and also collaborated to avoid injuries, either during the dance classes, or everyday. From this we worked possibilities of joints movement, axis, weight, tonus and creativity, aiming the individual expression. On the other hand, we sought to take the art to the patients/students, through the dance language, therefore, even existing some understanding that the art is important for the life and health, maybe a large portion of the brazilian society does not have yet a conception of art beyond that which comes to them by the communication vehicles and mass culture, that in most of the cases values more an “empty” beauty, than aesthetic and education aspects. One of the objectives of this work, so, was to change the vision about art of the patients/students, through exercises of dance which involved not only the body consciousness, but creative processes, to stimulate them to just not reproduce movements, but to externalize their emotions and feelings through these movements, making them true and not something performed mechanically, besides taking them to face their difficulties not as a limit that stopped them to perform certain movements, but as a way to get to their only dance. We didn’t expect that they thought in how the aesthetic result would be, but in how their bodies answered to what they wanted to transmit. In other words, the patients/students were taken to notice that, even with the physical difficulties imposed by the hemophilia, that condition not necessarily would prevent them to dance, because in those classes they were subjected of their own experiences and they could choose the movements. There, they could be whatever they wanted, and could develop their expression the way they were comfortable. With that, we expected also to contribute with a vision that not reduced these people to the disease or to the symptoms caused by it: they were subjects before – and independently – from being hemophiliacs.

It can be said that there was an interface to the dance with the health area – in this case, physiotherapy. After all, both work with the body and its movement, however, in different forms. While in physiotherapy the exercises are directed to movements rehab and pain decrease, in the dance they are directed to the own body consciousness, with the intention to not only improve mobility, but to develop the creativity with creation specifics exercises. The objective of the work was, therefore, study a way to develop the dance with hemophiliacs patients, who require some special cares, due to the pains and joint limitations caused by repetitives bleedings, observe how they develop themselves, which exercises collaborate or not for their development and which are the benefits provided to them, and also, bring a body-aesthetic education for the hospital environment, after all, even if the classes had some exercises with similar features to the taught by physiotherapists, the same were worked creatively, using images and integrating the body consciousness to the creation experience. Furthermore, it was intended that they rescued or increased their self-esteem, that sometimes is low, either for physical or psychological reasons. That was realized showing them their own evolution in classes, through videos and also, creatives exercises. From questionnaires applied to the patients/students in the first and last day of classes, of observations and shots, we did an analysis of the evolution of these patients/students and, thereby, we described what collaborated and not in this evolution. Thus, this article is structured in the following way: the topic 1 we approach the hemophilia, for better understanding about what it is and what it causes; in sequence, we discuss about how the classes were developed based in bibliographies about hemophilia. In topic 2 we talk about the experience of the first author with those classes and with the students, about how they evolved and which was the return and development of the students against the proposed work.

1. Contextualization of the and Findings in the Literature about Hemophilia

1.1 General Considerations about Hemophilia

Was conducted a literature review about the relationship between hemophilia and dance, hemophilia and movement restriction, physiotherapy and dance, physiotherapy and body technique, but we realized that there is a discrepancy in researches developed about these interrelationships, because the searches, carried out on the databases “Acervus – Sistema de Bibliotecas da Unicamp” and “Scielo”, selecting Brazil as region, brought no results. Although exist many productions about the treatment of hemophilia regarding a physiotherapeutic work that may assist these patients, by including the term “dance” as a filter of search there was the referred reduction of the results. Even if results had appeared contemplating the relation between dance and physical conditions of hemophiliacs patients, we speculate that these works would not make a specific cut for the aesthetic aspect and the artistic education, since the art-education area in Brazil, although counting with high quality of production, still faces limitations as the dissemination of knowledge into indexing databases.
In this topic, we describe what is Hemophilia and which physical conditions it can result that represent a difficulty to develop a dance work, as a good reason to developed it, in order of improving these people quality of life. Hemophilia is an hereditary hemorrhagic disease and there are two types: Hemophilia A, caused by factor VIII deficiency, and hemophilia B, caused by factor IX deficiency. These factors are proteins responsible for the blood coagulation; therefore, their absence makes the metabolism of the hemophilic person have difficulties in stop bleeding; depending on the factor’s level of coagulation, it can be classified as light, moderate or severe (Federación Mundial de Hemofilia, 2014). Rarely women are affected by the hemophilia, because, generally, they only carry the gene that transmit it and, against the hemophiliaics men who always transmit these genes to their children, women carrying that gene will not always transmit it. Therefore, if the father is hemophilic, the children consequently will be hemophilic, if male, and will be just carrier if female. However, if the father is not hemophilic, but the mother is carrier of hemophilia gene, there is 50% of chance that the children borns hemophilic if male and 50% of chances that be carrier of the hemophilia gene if female. Children can still be born with hemophilia even if their mother is not a carrier; in which case, the factor VIII or IX was unchanged alone in the baby body (Federación Mundial de Hemofilia, 2014). The bleedings can be caused by lesions, or so-called “spontaneous bleedings”, that occur for no reason. Such bleedings can be visible or not, and their manifestation occurs manly in the form of hematomas and hemarthrosis. (Brasil, 2011). The hematomas can be a signal of bleeding in the muscle-skeletal system that happens by direct traumas or by stretched with apparent cause or not; however, if the muscle is not close to the skin, there is no hematoma (Brasil, 2011).

Generally the most affected muscles at the upper end are the anterior portion of the forearm and, in the lower end, the iliopsoas, twins and quadriceps. With time, these bleedings cause the loss of elasticity and shortening of muscles, and if the extravasated blood is not fully reabsorbed, leads to the formation of capsules and cystis, called false tumor, because they form species of clots filled with blood. During these bleedings, the muscle contracts to protect itself and, thereby, ends damaging also the joints movement (Brasil, 2011). Hemarthrosis are joints bleedings that affect especially knees, elbows and ankles, compromising them, and if the repeated hemarthrosis are not adequately treated, leads to the synovitis, which is the inflammation of the synovial membrane due to the iron deposit inside it and in the articular cartilage. This means that there is joints degeneration, causing joints deformities and severe functional impotency. The hemarthrosis can be classified in acute, where the bleeding intraarticular is recent, and in chronic, when occur new bleedings before the articulation has recovered from the previous one (Brasil, 2011). When the bleedings occur in the head, throat, backbone, in the eyes and psoas muscles, require attention and redoubled care, but, otherwise, they hardly put the life in risk, unless they are related to very serious injuries or other medical problems (Federación Mundial de Hemofilia, 2014).

1.2 The Classes Development and the Concept of Multidisciplinary Team: How the Dance insert Itself in this Context?

Together with the read literature, the first author talked to physiotherapists of the State University of Campinas Clinical Hospital Blood Center, always very thoughtful, to take doubts and know information that were not found in the texts, to get a notion of which kind of exercises would be worked or not with the students. This ended up causing us to enter in the field of multidisciplinary and the transdisciplinarity5, because, at the same time that each one (dance teacher and physiotherapist) was focused in their area, to work with the same problem in the patients/students, there were also moments that we thought together about aspects that could be worked and how they could be worked, which defined the development mode of the classes. It was important to work the dance together with physiotherapy, because, despite the great body knowledge that physiotherapists have, there isn’t a knowledge in the body consciousness point of view, and, if there was, they don’t know how to develop it in their patients. Thereby, the physiotherapists had contact with which was proposed in classes and began to have greater knowledge about this subject, as well as the reverse also occurred: in contact wht physiotherapists the first author could understand more about hemophilia, and so, have more security to develop the classes. Therefore, we believe that the multidisciplinary greatly enriched all the parts involved. Regarding exercises, some could not be worked, but not many. What was really essential was to avoid impacts, too repetitive movements, and also full flexion or extension of joints. The last two cases were necessary because, as said one of the physiotherapists, due to synovitis, extreme or repetitious movements could snap the synovial membrane that is inflamed and cause bleedings.

5A team is “multidisciplinary when exist many professionals attending the same patient independently” (Tonetto, Gomes, 2007, p. 90), and is “transdisciplinarly when actions are defined and planned together” (Idem, ibidem, p.90).
After having greater apprehension about the conditions imposed by hemophilia, we began to search for books that could guide the classes elaboration and we found some references with issues related to body consciousness, dance as therapy, movement domain and creativity. Among them, we selected the texts of Calazans, Castilho and Gomes (2007), Laban (1984), Barbosa (2008) and Imbassai (2007) to base the proposed activities described in this paper. All these subjects that guided the bibliographic search was important in the physical and creative development work of the students. First because, as they in fact have some limitations and need certain cares, is of great importance that develop consciousness about their bodies, to decrease the risk of injuries and alleviate existing pain, besides enable that they start to feel and realize the whole body and not just the affected parts due to hemophilia. This can lead them to notice other movements possibilities, beyond the ones they imagine having, using different parts of the body, not just the parts with some limitations. However, we sought to also work the affected regions, with intent to improve the movement extension or, at least, not allow that this amplitude reduced further. About the creativity aspect, in particular, at first we had not thought to elaborate creation exercises, but, as says May, There are other ways of personal communication beyond the word: the art and music, for example, are the voices of the sensibility representants of a culture, transmitting meanings deeply personal to others members of the same or others societies [...] (May, 1971, p. 55). Thus, working the creative side of them would be important so they could, besides understanding how to deal with their pain and finding their own way to move, also could use these works as expression form, as a way to say by movements what they have difficulty or fear to say in words.

1.3 Body Consciousness versus Dance as Therapy

The exercises of body consciousness were of paramount importance in classes, because they led students to a more accurate rate of perception, both in relation to the body, as compared to the other bodies and space they occupied. Like says Nunes, By observation and perception of the simplest movements we start an awareness work, subtle, but of great effect. More important than the learning of any body technique is the body consciousness work, the tensions it keep, the blocks that stop it to follow the flow of life (Nunes, 2008, p. 34). So this could be worked, we have relied on four steps generally worked in a free course of body consciousness, indicted by Maria Helena Imbassai in her book "Sensibilidade no Cotidiano - Conscientização Corporal" [Sensitivity in Everyday – Body Consciousness] (Imbassai, 2007). They are: stretching, conscious relaxation, micromovements and use of space. It is elucidated to follow these steps:

- **Stretching** - generally done with the student lying on the floor, moving spontaneously. The objective is that, through the stretching, they can undo the excess of accumulated tension in daily life. The stretching is always stimulated during the class.

- **Relaxation** - the experience of an attentive passive state. It is about a supply, never a alienated abandonment. The relaxation predisposes the attentions and concentration levels desirable to work.

- **Micromovements** - are slow exercises, made with the student lying (in most cases), sitting or standing. The whole body is covered all the time. Each segment can be worked alone or together with other(s). The micromovements can present some difficulties to the beginner because of the required concentration. The leader task is conducting the students interest so they become aware, through their sensations: the tension degree of the segment that is being worked; the joints difficulties and possibilities; the connections between the segments, the bones mobility.

- **Use of space** - in this step, games, jokes and improvisations are proposed, but the dance is free, without choreographic requirement. With the music resource, the rhythm, the motor coordination and creativity are exercised through the ludic experiences, lived individually and/ or collectively. The suggestion is that the students seek references on the given material in classes and they experiment differents movements qualities like vibrations, swings, jumps, spins, balance, alternating efforts, flows, weights, intentions, using the three plans, freely: down plane (in the floor), medium plane (near the floor) and the higher plane (standing) (Imbassai, 2006, p.53).
What was intended to perform these steps with the Blood Center patients, as well as says Imbassaí, was “[...]
providing a physical and mental flexibility state, a readiness - without tension - which leads to the opening towards
the new, indispensable to the creative do” (2007, p.55). Thereby, it was intended to bring to the students a greater
dominion over their bodies and sensations, so that, they can search self-assurance and not retract theirselves due to
their pains, realizing that they can improve their conditions and that they are able to perform different activities from
the developed consciousness in their bodies.

This way it can be said that the dance ends acting as therapy:

The body consciousness is a pedagogical tool, of preventive character, although propose the correction and,
to work with constitutive elements of healthy and balance body-mind organization, this practice can be considered as
a therapeutic activity (Imbassaí, 2007, p. 54). With that thought the patients/students were taken, gradually, to meet
themselves, to start to have a harmonious life, without frustration or unnecessary vastness upon their bodies,
accepting their limits and, mainly, overcoming them.

1.4 Relations between the Creation Exercise and the Self-Assurance Development

As previously explained, the work aim was not to teach some kind of dance technique so the
patients/students could perform their creation exercises, but, through the deepening and broadening of the
perception about their bodies with body consciousness exercises, take them to the contact with their sensations,
emotions, feelings and desires, in order to express them and, somehow, go beyond them by movement. Therefore, the
students could realize that they have the capacity to express themselves, however the limits they have, and notice that
the important is not the perfect execution of a movement, but rather, the conscious to do it in order to not harm
themselves. They also realize that the movement does not come “out of nowhere”, but a search and understanding
about themselves are needed so it arises naturally, after all, the goal of the body consciousness is to make changes
from inside to outside and not mechanically (Imbassaí, 2007, p. 55). Thus, it is possible to express something with
meaning and value, which is important so they could say what they want and need so they can, as previously said,
follow the flow of life, being themselves, not afraid of what other people would think/ assume or not about them. As
pointed out by Imbassaí, The body consciousness can collaborate for a ‘deepening of self-consciousness’, bringing
back the sensibility that was lost by people due to society charges and ways to live in it. (Imbassaí, 2007, p. 49).
Thinking about it, also, we sought that besides the body consciousness generated in students, was generated their self-
assurance in relation to the fear that they have about their bodies.

2. Description of the Project “Dance Teaching for Hemophiliacs Patients of the Clinical Hospital of the
State University of Campinas”

2.1 The Blood Center Patients and their Physical Conditions: Difficulties and Challenges Found in the Beginning
of the Activities

At the first day when the first author went to the blood center to talk with the physiotherapist Márcia P.
Matta about the classes that she would minister and about what expect from these classes, she was invited to an event
that would occur in the next week due to the World Hemophilia Day, April 17th, so she could meet the patients who
would participate in the classes, so she could observe them in order to perceive their bodies and difficulties. Thus, it
was possible to notice that a large majority had difficulty in marching, mainly the older patients, while others seemed
to have no difficulty making any movements. Two weeks later she returned to the blood center and, before starting
the practical classes, applied a questionnaire to be aware of the students situation, the purpose of preparing the classes
appropriately, and also, to find out what the patients expected from the dance classes. At the first class there were four
students, being three adults, only one female, and one child. But as the time went by, only two students (the woman
was one of them) continued attending to all the classes, and the child sporadically. The physical space was greatly
reduced, which hindered the classes development with a larger number of students. On the other hand, it was positive
to perform the work with a few students, because in the beginning the first author was apprehensively, afraid of
causing problems to them or that the exercises were not appropriate. This fear diluted completely as the
physiotherapists were offering support, following the activities at all the time and, as they said nothing about being
harmful to patients/students what was being done, the work was becoming more mature. The first class was about
diagnostic evaluation, which brought each student an individual knowledge and were allowed to see which was the
difficulties and needs of each one. Thereby, the exercises were elaborated having in mind such difficulties and needs.
2.2 Structuring Classes: from Body Consciousness to Dance as an Aesthetic Experience

We live in a world/time that deals with the body on a detached way, and so we get to a body aesthetic education with a great majority of people, we need, before this step, of an entire work of knowledge/recognition of the own body.

For that, as previously said, the classes were developed within four bases worked in body consciousness exercises, that are: stretching, conscious relaxation, micromovements and use of space. Within these bases, were developed some other dance elements, like axis exercises, balance, marching, tonus, speed, weight and stretching, thinking always in ways to work them in order to collaborate with the improvement of the students difficulties without causing some kind of problem, like pains or bleedings. The exercises couldn’t be of much impact or with too many repetitions and, therefore, the classes had to be carefully thought. Besides, all the exercises that the patients/students performed lying were made on a stretcher, both because the room floor was made from cold tiles, and by the fact of the difficulty that the patients/students had to lie or sit down. An important resource was to show images of the joints and backbone to the patients/students, which facilitated, for them, the understanding of how the movements happens.

The classes followed the following chronology:

- **Stretching** - with the students lying on the stretcher
  - Conscious relaxation - still lying on the stretcher, was required that: 1) Pay attention to the breath, in tense and painful parts of the body, to the weight of the bones and muscles; 2) sometimes, were conducted passive motion exercises, that consisted on guiding the students to loose the weight of their members on the teacher's hand – first author of this paper – so she could move their members, exploring the possibilities of movement of their joints and asking them to try to visualize the bones and muscles moving inside the joints that were being moved. The objective was to have a deeper perception of the movements. During the relaxation were used images like: air filling the whole body, air circulating and massaging the muscles, air massaging the tenses and painful areas, water running down the spine and water filling the joints. It was realized that this way, besides relaxing more, they could have a better perception of what was asked of them, and their performance during other exercises were more effective.

  - Micromovements - 1) we explored while standing all the possibilities of each joints movements, from the upper torso to the knees; 2) It was requested to sit on the stretcher to explore the ankle and feet joints. With time, was realized that lying on the stretcher they could have a more deeper exploration. Thus, they were always oriented to start lying and, then, standing movements exploration also were performed. In the exercises they performed when were lying, was a work of recognition of the body parts, in which were asked them to start articulating the toes and slowly passing the move to others joints (ankles, knees, hip, fingers, elbows, shoulders and, finally, spine and neck), exploring for a time each joint. This brought the notion of body scheme and facilitated the posture understanding, as the possibilities of each joints movements. So they could get a better performance, images were used in this moment too, like imagining that the spine was an earthworm or thinking that they were an earthworm.

  - Stretching - using rubber elastic bands, were worked the legs stretching: 1) the students put the elastic on one foot and worked the flexion and extension; after, the lateral and medial rotation of the ankle (both first with the leg supported on the stretcher and then, with the leg high); 2) with the leg high (each one in their limits) and with the elastic on the foot, they made small circles outside and inside, to work the hip joint. 3) with the leg high and the knee slightly flexed, pushed the elastic (without further extend the knee) and back to the starting position; 4) they tied the rubber elastic band on both feet and worked the hip lateral rotation pushing the band with the foot; 5) they held the elastic in one foot at time so they worked the hip medial rotation; 6) with the rubber elastic band on both feet flexed, they held each end of the band in one arm and pulled it, making a kind of abdominal exercise, at the same time that they worked the hips joint.

- Axis 1) they were with both feet supported on the floor and shifting only the torso forward and sideways, and then they made a half circle to the right and left (side-front-side); 2) they supported on the stretcher and stayed with just one feet on the floor, raising the leg forward and sideway and also making a full circle, and they made these exercises supported until they had confidence to make them without the stretcher support; 3) they extended and
flexed the leg, left the knee to knee, but without extending or flexing too much to not affect the joint; 4) they pulled the leg in *passe en dehors* and then, opened in *passe en dedans*. Note that those *ballet* terminologies were used with the students, having in mind the cultural aspect and the dance appreciation as art - to these patients/students, the access to *ballet* classes was never been provided in their school education.

- **March:** They walked forward and backwards aware of how the feet articulated, the weight that was transferred from one step to another and also to how each one stepped. This was a challenge for them, because some had one leg shorter than the other, or else, a knee that not stretched completely, which hindered the march. Gradually, however, they were understanding where to support the weight and the posture they should take to give them more stability.

- **Touss** 1) were made arm movements: abduction and adduction, front and behind, one forward and other backward, arms going up over the head and down crossed in front of the torso, like a *port de bras*; 2) then repeated it with two pound dumbbells in each hand. Thereby, they could perceive more easily the difference between a light and strong tonus, which, over time, collaborated so they could make these changes without the dumbbells. The perception of the difference in the muscle tonus quality appeared, after, in their creations.

- **Sequences** A few days later, when they passed to understand better what was expected in the exercises, we started creating movement sequences that involved which had been working in classes (articulation, balance, weight, tonus).

**Creation** generally was given a kind of “homework” with various themes or proposals (space, extent, time), to the students create sequences to be shown on the next class. From this, new proposals were made based on what they had done in the previous creation exercise (speed, change the extent or space), that sometimes was explored during the class or also were made in home to be shown later. However, we realized that this way we didn’t have much results; then, we passed to use objects, like balls, tissues and weights (to they could notice the tonus difference). Also we used very different musics, like, for example, a well fluid and other in *staccato*

Along with all this individual perception work, also came the perception of the colleague, according to what point Imbassai: From the individual perception it is possible to realize that other structures, other bodies, other people also move and, more than that, they interrelate. This leads to an another(s) consciousness, resulting in the social body (Imbassai, 2008, p. 56). This consciousness of the social body is important to, through the interrelationship with other bodies, the students note which are their similarities and differences, that are as important as - or even more important - the equality of their bodies, because this is the wealth that makes each person an unique being and, in dance case, liable to explore and create their own way to express themselves. This perception was important for when we started to insert exercises of contact improvisation in the classes, in which, besides they have consciousness of their own bodies, also needed to realize and listen to another body, so the exercise could flow. Going back to the question of individual consciousness, it was important not only to the sensibilization of the students bodies, but also promote their aesthetic experience, because “The piece of art is an objectification of the feelings, i.e., its concretion in a symbol” (Duarte Júnior, 2007, p. 89). In this case, we relate the piece of art to the students’ creations, that, imbued with feeling and sensations, turned it in moving. In other words, the dance that they made was the objectification of their feelings, and each movement was a symbol of a inner process.

### 2.3 Students Development during the Practice

In the first few classes, what was possible to realize, even by the students own speak, was an improvement in the posture and also in the self-consciousness. By the third class, they had already put themselves to the exercises realization, without the need to call attention to the posture. Related to self-consciousness, they corrected themselves when something was wrong and they noticed what was necessary to the realization of the proposed work, for example, activate the abdominal muscles or broaden the foot support on the floor. They started to correct the trampled by themselves when realized that they were supporting more in the outer or inner border of the foot.

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6 *Passe* is a ballet step that consists in moving up the knee passing the toe (hallux) through the leg that is based until arriving in the knee-length of the base leg.

7 *En dehors* is an expression used in *ballet* which refers to when the leg is in medial rotation (to inside).

8 *En dedans*, in its turn, is when the leg is in lateral rotation (to outside).

9 *Port de bras* is the slow and continuous movement of the arms realized in classical *ballet*. 
Most of these perceptions appeared without saying anything. We believe that all of this is a great achievement, to the teacher as to the students, because the work goals were achieved and, also, started to being generated a better quality of life for them. Another important point was the improvement of the students performance in creative exercises. In the first months we couldn’t work much this part, because we were more focused on working the joints moves, posture and self-consciousness. The creation exercises started to be developed from August, when we started to insert objectives, the musics and contact improvisation, previously mentioned. The insertion of these elements generated more visible results, with more peculiar movements, due to the perception that each one has about what were offered to them as an impulse of the creation. They had also become much more confident and actives corporally, performing, including, movements that they did not perform during the classes due to said difficulties. Including, in the final questionnaire applied to the patients/students with some questions about the classes, one of the participants gave the following answer when was asked if the creation exercises collaborated in their performance and what collaborated: “Yes, in movements creation which I thought I was not able to do, and now I do.” Besides that, in contact improvisation exercises, was possible to realize that there was great respect for the other’s body limits. To discuss about the perceived results in patients/students, we opted to do it in the case report format and, for this, we will talk about only one of the students, both by the fact that she had major developments, as the fact of being female, wherein the condition of hemophilia is rare. For identification purposes, we use the abbreviation P1. P1 had the knees and hip joints more affected by the hemophilia, which caused a shortening of her right leg, by the fact of not having the joint space between the femur and the hip, besides that the same leg remained in medial rotation, hindering the movement of sitting, squat and deambulation, causing limp. In relation to the knees, there was a difficulty in their flexion, which ended up harming all other movements previously mentioned, but, mainly, the marching.

In the first month of classes, in marching exercises, P1 said that she started to pay more attention in how she stepped, not only in classes, but also everyday. In a few weeks the result was perceptible, because was possible to notice, during the classes, that she passed to use naturally all the foot base in the exercises, not only falling to the outside or inside border of the foot, and that consequently collaborated to the improvement in her balance. In the second month she gave us a feedback of something that happened out of the class, when she said that, to sit in the car, normally she needed to leave the seat lying to not be uncomfortable and with backache, caused by the hip joint tension, but after the classes she could leave the seat sitting, keeping relaxed and without pain. The classes were then developing and, gradually, P1 was presenting evolutions. She passed to limp less, gave larger steps and moved herself more easily and with more freedom. Out of the observations we could do in classes, always had feedbacks of the participant telling us something that she had managed (like sitting the seat car) or explained why she had improvements elsewhere, which was very important, because was possible to see that what was worked with them in classes generated results. In the final questionnaire, in the question about the improvements and changes in their bodies and in everyday, she gave us a close response to the feedback we gave in class: “improvement in the knee, strengthen of the muscles, balance, arms movements and even the way to walk. Improved marching”.

Regarding limping less and giving larger steps, P1 said that in dance classes, with the exercises of body consciousness, she passed to feel and perceive more her own body. With this, she could notice that due to her difficulty in walking, she tensed her whole body, but, mainly, the ilio-psoas muscle, that perhaps limited some movements; so, she passed to give more attention to this to try have more movement range and less pain. With time, she noticed the improvement and passed to relax the region, which collaborated so she could walk more easily, limping less and providing larger and more confident steps. Consequently, from the time that she could dilute the tension in the ilio-psoas, also began to let the muscles of the entire body less tense, which helped her movements during the classes become more extensives, lighter and more articulated. About the medial rotation of her left leg, with the consciousness that has developed about leaving her muscles and joints relaxed, she began to perform more easily the rotation exercises give in classes, because, in the first classes, her left leg had no lateral rotation, but in the course of time, she started to be able to make a small rotation, which helped her to start having a little more mobility in her hips.

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10 As Stake, In Denzin e Lincoln (2001), quoted by Cesar (2014), “[...] the Case Study Method allow analyze a situation where it can not interfere with manipulating relevant behavior and the data can be collected through based sources in: reports, documents and observations” (p. 7).

11 Marching.
These exercises were given in all classes, until she started being able to rotate the leg with some strength and generating tension in the hip to keep the foot parallel, and so, after four months, she could keep her foot this way naturally, without tension or force anything. But to sit, besides her consciousness about the muscle and joint relaxation, the fact of not having more space between the head of the femur and the hip hinder the movement required for this. These were her most relevant advances, however; other things that might be noticeable is that the creation classes gave her not only confidence, but also more body expression and movements performed not for the aesthetic, but for internal perceptions that impelled her. It is worth to remember that P1 did not do the exercises only in classes days, but repeated them at home and, sometimes, was made even adaptations, for example, in the exercise given with elastic for leg rotation. Lying, the teacher tied both her feet with a rubber elastic band and asked to do a lateral rotation with the legs and she said that, in home, she tied the elastic in the handle drawer to hold the leg in lateral rotation while she watched television. Therefore, we believe that her advances were bigger because she performed the exercises also out of the classes.

2.4 Creation Exercises: Dance as Dance, and not as Therapy

In August, an occupational therapist of the blood center informed that in October they would do an event for Children’s Day and they would like that some choreography with the students were developed, so people could see and hear about the work that was being done with them. It was decided then to create two choreographies. The first, using jazz dance movements and an excerpt of the musical Moulin Rouge, and the second, with a song not very known and with elaboration of the elements worked in classes, besides parts which was given freedom so the students could create their own moves inside the choreography. So, talking to the guiding about the first choreography, The question “Why Moulin Rouge?” came up. At first, the choice was made without thinking so much about that, however, after reflecting, we concluded that this choice was made because it is a reality closer to them, something they were used to seeing, that they “recognize as dance”, and that was the definition what may appear to be beautiful for them. As Duarte Júnior says, in the moment of the aesthetic experience occurs a full involvement of the man with the aesthetic object. The consciousness no longer seizes according to the rules of everyday “reality”, but opens a relationship without the partial mediation of conceptual systems (Duarte Júnior, 2007, p. 91). In other words, the Moulin Rouge represented both teacher and participants an experience of aesthetic fruition not mediated to conceptual reasons, an element that became a pleasurable activity, as it were. Through the relationship and experience that the participants had with Moulin Rouge, it was easier to deconstruct the view that to be dance it has to be beautiful and virtuous, because they were all the time stimulated to search their version of the Moulin Rouge.

After we started to work with the other choreography, that would bring even more the movement individuality of each one, because it was used an unknown music and that didn’t have a “reference” in dance. This was perhaps the richest moment, because, as they passed by the two experiences, they realized that expressed more themselves in the second choreography, constituted by movements that they have created based on what they felt, in opposition to the Moulin Rouge, which the movements were defined by the teacher. As noted by the authors, the movements created for the second choreography came imbued with so much truth that, exactly for that, were beautiful. The way P1 used the time to move, in this case when the music not “dictated” the duration of the movements, was very peculiar and, for that, was translated into real gestures. Was possible to see her truths to watch her dancing in her own. Even the borders between the professional and amateur are diluted when non dancers get in touch with their own conflicts and express themselves through the movements. Not without reason, the creation experiences with non dancers have been carried in the dance history since the 1970s (Andraus, 2014), moment that effectively the conceptions about technique and aesthetic in dance were redefined beyond the tradition of reproducing mechanically movements dictated of heteronomous form.

Final Considerations

With this work we aim to bring a better quality of life to the hemophiliacs patients of the Clinical Hospital of the State University of Campinas, in Brazil, so that they get along with themselves, accepting and understanding their bodies and finding ways to deal with their difficulties and limitations without feeling unable. Furthermore, we tried to generate more body consciousness, to understand how they moved and what parts were moved, and thus, avoid pain and lesions. Inside this work was developed a creation process with them, as a way to lead them to express themselves through the movements and encouraged them to seek their own way to move, without relying on stereotypes.
In this way, we believe that was stimulated the self-confidence of these people, breaking with the verticalized relations in which the “patient” - seen as a passive person, as the word patient itself indicates - only executes movements that the therapist or doctor ordered, and the way it was oriented. Provided that there is body consciousness, people, even having delicate physical conditions and requiring special care, can enjoy the freedom to move, because they begin to know which movements that could harm them. Is fulfilled, thus, the role of art as an important way of education, to the extent that fosters the person autonomy and, in this present work, suggested a patient’s point of view of the humanization in the health area.

References


