ALTERNATIVE SUPPORT FOR FAMILIES WITH AUTISTIC CHILDREN IN LITHUANIA

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Abstract
The article discusses about the possibilities of alternative social, educational and medical help to autistic children (under age 6) and their families by means of qigong massage elaborated on the basis of traditional Chinese medicine; moreover, the article introduces the initial result of the pilot study accomplished in Lithuania. The qigong massage therapy has been scientifically shown to improve the behaviour and development of young autistic children and diminish parents’ stress related to raising an autistic child. The experience of the families in the USA witness distinctive changes in the development and the sensory system of an autistic child due to qigong massage as follows: children started speaking, they have better sleep, they have better attention and concentration, their communication improved, and parenting stress is reduced. A team of researchers of the Faculty of Health Sciences, Klaipėda University started research into the possibilities of application of qigong massage as integral and complex social, educational and medical help to autistic children and their families in Lithuania in 2011 and since then has been developing it. The outcomes of the pilot test in Lithuania are consistent with aforementioned in the USA.

KEY WORDS: Autistic children, family, alternative support, qigong massage.

Introduction
The article is the first scientific publication on the idea of qigong massage in Lithuania which develops a discussion of it in the context of alternative social, educational, and medical help to autistic children and their families. The predominating positive and tolerant views of the disabled in Lithuania, the optimized legislation basis, and critical reflection on human rights constitute a prerequisite for the integration of opportunities for alternative social, educational and medical help to the disabled. However, in Lithuania, a view of alternative or otherwise called forms of complementary medical treatment has not been precisely defined. There is no consensus amongst specialists and the public opinion in terms of either methods or the opportunities of their application. The space of discussions on alternative medicine and help becomes even more indefinite when talking about autism, which has complex origin and polyfunctional substance in education and medicine. Therefore, when discussing any of the
methods, its integral introduction in the context of social, educational, and medical factors is of great importance.

In Lithuania social educational support for families of children with disabilities is provided in kindergartens (special or general settings) and in schools (special schools, compulsory schools by providing special educational support). Schools and kindergartens, according to the special needs of children with disabilities, employ special pedagogues, speech therapists, physical therapists. The laws and regulations mandate the parent’s formal right to choose the educational institution. However, in reality parent right to choose the educational setting for a child is challenged and in many cases rejected. It is an ongoing discussion of how many special schools we need in Lithuania, how many specialists should work with the child. Often decisions are based, primarily, on the social political interest and not on the child’s and family interests. Social education service for families of children with disabilities is changing alongside with the concept of Welfare State. Social education services decrease due to the notion that the State cannot provide immeasurable social support for all people; moreover, a person and the family has to take responsibility and participation for social welfare. In such context parents and specialists cooperation is very important.

In Lithuania numerous scientific studies report about existing problems in parents and specialists cooperation in many different settings as following early intervention center (Ališauskienė, 2005), special school (Gerulaitis, 2007; Ruškus, 2002), general school (Miltenienė, 2005); and dolphins assisted therapy (Kreivinienė, 2011). However, in aforementioned studies there were no special focus on autistic children. Kreiviniene (2011) notes when parents are not satisfied with social, educational, and medical support they are looking for alternative support methods such as Dolphins therapy, hypotherapy, etc.

There are growing numbers of children with autism in Lithuania, and a growing interest on the part of physicians, educators, social workers and families, in learning ways to restore the child’s natural systems for health and development using holistic approaches such as diet, massage, exercise, natural medicine and other kinds of alternative healing methods. These fall under the heading of complementary and alternative medicine (CAM): a group of methods that can be used to complement conventional medicine, prevent or lessen the impact of illness and in some cases serve as an alternative to conventional therapy. They consist of ancient and modern methods from Eastern and Western healing traditions world-wide. They are of interest to researchers in that there is a large and growing body of international research investigating their effectiveness. And they are of interest to ordinary citizens because, although an initial period of training and support may be necessary, not all of them have to be delivered indefinitely by specialists, and, once trained, individuals can use them for self and family help.

In Lithuania, we already have experience with the positive effect of scientifically proven alternative methods for families of children with disabilities using Dolphins Assited Therapy (DAT). During 2003–2009 years in Lithuanian Sea Museum in co-operation with Klaipeda University scientists there were conducted valuable researches proving positive effect of DAT on both development of children with Down Syndrome, Autism, Cerebral Palsy, emotional disturbances, behavioral problems (Rugevičius,
Kirkutis, Žakaitienė, Šostakienė, Kirkutytė, 2006; Kreivinienė, Vaičėkauskaitė, 2010, 2011). Parents reported about sustained changes in child’s development as following increased motivation for independence, improved social skills, and communication which imply state that DAT creates a significant resources for child’s development. Moreover, parents reported about significant positive changes in family’s sense of coherence, communication, parent’s self-confidence. Furthermore, parents reported for need to be supported in prolonged programme after DAT. This represents the shining example of alternative methods for children with disabilities used in Lithuania.

There are only a few scientific research papers with major focus on autistic children as follows: Lesinskiene (2000) and Ivoškuvienė, Balčiūnienė (2002). In numerous scientific family oriented researches conducted by R. Jusienė (1999), J. Ruškus (1997, 2002), J. Pivoriienė (2003), S. Ališauskienė (2005), R. Vaičėkauskaitė (2005), B. Kreivinienė (2011) the problems of autistic children and their families are analyzed in general context of social integration. Research scientists at KU recognize the need for additional scientific research with major focus on autistic children. We are particularly interested in exploring research-based CAM methods for early intervention for children with disabilities that could be suitable for application in Lithuania.

The Lithuanian academic community, specialists of kindergartens, and parents of autistic children were introduced with qigong massage by professor L. Silva in the winter of 2011 at Klaipeda University. The outcome of the contact was a pilot study introduced in this article. However, our experience with qigong massage as an idea is not limited to the pilot study. Presently, under the leadership of professor Louisa Silva, trainings of parents of autistic children (under age 6) and of specialists take place, and research is conducted in collaboration of Klaipėda University researchers and specialized children educational institutions of the city of Klaipėda “Svetliačiok” and “Sakalėlis”. The method is unique as it creates a synergy system of parent and specialist collaboration which covers the fields of child’s development, his sensory system, and parents’ experienced stress. The qigong massage of professor Silva Louisa, based on the experience and achievements of traditional Chinese medicine, has been taking root in the practice of many countries. Furthermore, we expect that the method will be integrated in the system of Lithuanian social, educational, and medical help for autistic children and their families.

1. Paradigms shift of social, educational support for families with disabled children in Lithuania

In Lithuania for 50 years during soviet regime period social, educational and psychological support for children with disabilities was based on defectological paradigm. Children with disabilities were considered as abnormal, so the support was delivered in segregated settings and oriented to normalization and adaptation. It was a point of view that once deficits are remedied and a list of social skills is developed, individuals with disabilities will be able to participate in society in an independent manner. This approach has failed because having the necessary skills alone was not enough for individuals with disabilities to
meet the environmental challenges and expectations. Moreover, segregation of family and a child caused great stress for both a family and a child.

In Western Europe and the USA the problem of social segregation was challenged by human rights movements in the 6th decade of XXth century. However, Lithuanian society has been undergoing a democratic transformation somewhat later. In the name of equal rights, the social participation of all people by voluntary decision, especially those with disabilities, became an important issue, as well as a great challenge, to Lithuania’s democracy since the restoration of independence in the 1990s. The Education Reform Act of June 25, 1991, consolidated democratic principles of education in the country and all children, even those with severe and profound dysfunctions, were considerate as educable. Lithuania’s first post-communist Constitution (1992) affirms the determination of the Lithuanian nation to strive for open, just and harmonious democratic society. It claims that every child must attend compulsory education until 16 years of age. The Act of Special Educational Provision for Children with Special Educational Needs in Mainstream Educational Institutions (1993) is the first basis in legislation for integrated education of children with SEN. Pupils with SEN can attend mainstream group or class, following the mainstream curriculum, partly in a mainstream group or class, partly in a special group or class; at a special group or class. It also mandates the parent’s formal right to choose the educational institution. Special Education became as a service instead of place. The Republic of Lithuania Law on Education (2003) article 15 defines that Special needs education can be provided by any school that offer compulsory or comprehensive education and other educational providers and in sometimes – special schools.

Social educational services change according to the human rights discourse. In 1992 Lithuania joined the Convention on the Child’s Rights of The United Nations of 1989, which was ratified by the Seimas of the Republic of Lithuania on 3 July 1995. The Seimas of the Republic of Lithuania adopted children's rights Protection Framework Act on 14 March 1996. This law ensures all children’s fundamental rights, freedoms and responsibilities; moreover, it guarantees the rights and freedoms protection in Lithuania. M. Brocklehurst (2004) indicate points of the Convention on the Rights of Child (1989), which require social integration of all children as follows: 2, 3, 7, 9, 17, 23, 27, 28, 29, 30, 31. To implement aforementioned items the concept of “School for All” is declared in many documents, and in particular in the National Education Strategy for 2003–2012 of the Republic of Lithuania. Together with other European countries Lithuania follows the concept of “School for All” where every child receives adequate attention and services, depending on their individual needs. The concept of National Policy of Child Welfare, approved by The Seimas of The Lithuanian Republic in 2003, shows the aim to enable every child to grow up in the family, by developing the infrastructure of social, education, medical services.

Since the 1990s social, educational and psychological support for people with disabilities is based on social integration (inclusion). The main principles of social integration for people with disabilities are defined in Law of Social Integration of People with Disabilities (1991, 2004). It was believed that essential points for social integration are as follows: to change the attitudes of society; to normalize social environment,
to declare laws. However, J. Ruškus and G. Mažeikis (2007) in his critical and reflective study points out that in Lithuania social integration became formal and declarative. Obviously, it is not enough to remove physical barriers, and change psychological attitudes; still more, it is important to strengthen the agency of people with disabilities which are essential for genuine social participation in the context of social integration. R. Vaičekauskaite research (2008) revealed possibilities to empowering children with disabilities for autonomy that is essential for agency. Furthermore, qigong massage is important for (re)building agency for children with disabilities, and self-confidence of family as a system is fostered as well.

2. U.S. experience with qigong massage as an alternative and complementary support for families of autistic children

Autism is the most common childhood disability in the U.S., affecting 1:88 children (U.S. Center for Disease Control and Prevention, 2012). Early diagnosis is possible, requiring the presence of delay of social milestones and abnormal behavior by age three. Early intervention offers the possibility of remediating social and language delay before the child begins primary school. There is significant support in the U.S. for alternative and complementary medicine research, and qigong massage, a treatment based on Chinese medicine, has been shown to be a promising early intervention treatment for pre-school children with autism.

Research on qigong massage treatment of pre-school children with autism took place in the US between 2000 and 2012. The research involved: 1) developing a model for autism that included co-morbid sensory and self-regulatory symptoms (Silva, Schalock, Ayres, 2011); 2) developing and validating outcomes measures for qigong massage treatment of autism (Silva, Schalock, 2011; Silva, Schalock, 2012); 3) developing and validating curriculum and training materials for parents and specialists (Silva, Ayres, Schalock, 2008); and 4) evaluating outcomes of two intensities of treatment, one parent-delivered with specialist support, and the second dual parent-and specialist-delivered (Silva, Schalock, Ayres, Bunse, Budden, 2009; Silva, Schalock, Gabrielsen, 2011).

The model proposes that delay of social milestones in autism arises from delay of earlier self-regulation milestones relative to orientation/attention, and self-soothing, as well as abnormal sensory responses. Qigong massage normalizes sensory responses and provides a daily physical stimulus that stimulates nervous system self-regulation. Treatment is given by the parent for five months and supplemented with treatment by trained specialists. Parents are given ongoing support for five months as they learn to give the massage and adjust it to the child’s responses. Experience with pre-school children indicates that, with training and support, parents and specialists are able to successfully learn the massage and effectively reduce the severity of autism.

After five months of treatment, results show improvement of sensory and self-regulatory abilities, improvement of social skills and behavior, and reduction in parenting stress. The massage is effective when given to 3–5 year-old children. As yet, there is no research investigating qigong massage with older children, although experience
indicates that it is more difficult to implement the program, and results may be less significant with older children.

4. Initial Lithuanian experience with qigong massage

In 2011, Prof. Dr. Louisa Silva was invited to visit Klaipėda University and conduct a lecture for professionals and a training workshop for parents of pre-school children with autism. Due to the shortness of her visit, it was not possible to train specialists to provide ongoing support to families. Data was collected on whether families were successful in completing the five-month intervention without ongoing support, and whether they were able to achieve the same results as families who received ongoing support.

Twenty nine families declared interest in learning qigong massage. They received 3 hours of training by Prof. Dr. Louisa Silva at Klaipėda University, Health Sciences Faculty, and were asked to apply the massage once a day for five months. Families were asked to complete online pre-test and post-test surveys consisting of two questionnaires as follows: Autism Parenting Stress Index and QST Sense and Self-Regulation Checklist. Twenty families completed the online pre-test surveys. We can perhaps conclude that the 9 families who did not complete the initial surveys were in need of specialist support from the very beginning, and not receiving it, did not start the massage. Data from the remaining 20 families indicates that children were aged between 3 to 14 years old. Eleven families had children between three and six years old, the most suitable age for qigong massage. Four families had children aged seven, and three families had children aged 8, 10, 14 years old. Mothers’ ages were from 26 to 47 years old. Parents came from all over Lithuania. There were 18 boys, and two girls.

Of the 20 families who completed pre-tests, only 8 families completed post-tests. Of these, only 5 families succeeded in applying the massage for five months. These were families with children from 3 to 7 years old, having autistic boys. From this data, we can conclude that specialist support is required for families both to start and to continue the massage after the initial training.

Any conclusions about the effectiveness of the massage are limited by lack of assessment of fidelity with massage procedures, both in terms of whether the massage was given every day, and in terms of whether the massage was given correctly. This is a direct consequence of lack of ongoing specialist support, as specialists would normally assess fidelity, and provide ongoing training so that massage is given correctly.

The 5 families who gave the massage for five months reported decreased parenting stress, and improvements in child’s eye contact, attention, calming and sleep. Of the two instruments used to evaluate outcomes of massage treatment, changes in the Autism Parenting Stress Index were more significant. Data suggests that to obtain significant changes in the Sense and Self-regulation Checklist, ongoing specialist support is necessary.

In 2012, under the auspices of the Fulbright Specialist Scholarship, Klaipėda University invited Prof. Dr. Louisa Silva to return and train a group of specialists to provide ongoing support to parents. We wished to conduct a small replication study with
Autistic children under age six. A group of 6 motivated and experienced special education, physical therapy and occupational therapy specialists was trained, and data is being collected on ten children on the autism spectrum, under the age of six, who are receiving the qigong massage program. The research is being conducted in cooperation with special kindergarten “Sakalėlis” and special school “Svetliaioki” of Klaipėda city. The kindergarten is an ideal place to implement CAM therapies and provide training for the two groups most concerned with young children with autism: parents and kindergarten specialists; moreover, there is ample access to children and parents, the specialists provides both physical and educational support to children and families, and the professionals involved are experienced and oriented towards helping children and families, and promoting development so that children can reach their potential.

Conclusions

In Lithuania, a view of positive aspects of alternative or complementary medicine is just forming. Lately, alternative medicine has been manifesting itself in different forms: dolphin therapy, hypo therapy, or traditional and non-traditional Oriental medicine. The awakening by massage of inner powers of autistic children has long been recognized in a number of countries in the world. The first outcomes presented in the article do not prove that the qigong massage has already taken root in Lithuania. However, the first outcomes reveal the potential opportunities both in the social, educational, and medical contexts. Furthermore, a researcher team of the Faculty of Health Sciences, Klaipėda University, in collaboration with professor L. Silva, has been developing research into justification of the possibilities of qigong massage application in Lithuania since 2011.

Alternative and complementary medicine is widely used in Europe as a safe and non-invasive treatment that can be used together with Western scientific treatments for a wide variety of illnesses and conditions. U.S. research with qigong massage has been conducted, not only in children with autism, but also in children with other disabilities such as Down syndrome and Cerebral Palsy. The research is unusual in that it expends a significant amount of time and energy in training and supporting parents to give the massage treatment to their children, rather than just providing the treatment with specialists. From a social and public health perspective, it is ideal to train and support parents to provide helpful daily treatment to their child. Klaipėda University is interested to explore whether it is feasible to introduce this kind of treatment in Lithuania in the social context of kindergartens. Initial impressions of KU researchers indicate that qigong (re)builds agency for children with disabilities. Moreover, self-confidence of family as a system is fostered as well. A full report of data gathered from the second study with ten children will be presented in September.

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