

Addressing Anxiety, a Comorbidity of Autism Spectrum Disorder: A Case Report Using Qigong Sensory Training Methods

Mardi Crane-Godreau*, Peter Payne

Geisel School of Medicine, Dartmouth, USA

ABSTRACT

Anxiety is a commonly occurring co-morbidity of autism spectrum disorders. Estimates of its frequency vary from 11% to 84%. It is the most frequently cited source of distress among those with ASD. This case report of anxiety in an 11-year-old boy with a medical diagnosis of autism and severe anxiety disorder details medical and social history of anxiety and panic attacks before and after receiving Qigong Sensory Training (QST) therapy. Significance of the use of non-pharmacological approaches that aim to address developmental neurological deficits is discussed.

Keywords: Anxiety; Autism; Asperger's syndrome; Diagnosis; Paediatric; Gastroenterologist

BACKGROUND

Anxiety is a commonly occurring co-morbidity of autism spectrum disorders. Estimates of its frequency varies from 11% to 84%, with a median around 50% [1]. Age, cognitive ability, specific diagnosis within the spectrum, and source of the report of anxiety (self-report, parent, teacher, questionnaire, medical diagnostic interview) are responsible for divergent reports, as well as the fact that there are very few instruments specifically validated for use in an autistic population [2]. Those with diagnoses of Asperger's syndrome, or high functioning autism, have the highest reported incidence of anxiety, possibly due to greater capacity for understanding and reporting their own situation [3]. It is the most frequently cited source of distress among those with ASD [4]. The diagnosis of anxiety differs in those with ASD and is complicated due to the similarity of anxiety symptoms and symptoms of ASD. For instance, the lack of social skills in those with ASD may manifest as symptoms similar to social anxiety disorder, and the stereotyped repetitive behaviour associated with autism may resemble obsessive-compulsive disorder; nevertheless, these are distinct and dissociable conditions [1]. However, there is a reciprocal relationship between autistic symptoms and anxiety, such that each may exacerbate the other. It is believed that anxiety in autism can be treated separately from the autism itself, using modified versions of interventions developed for neuro-typical populations. It has been suggested that conventional psychosocial treatments for anxiety be modified towards simplicity and concreteness, especially for younger subjects and those with lower cognitive capacity [1]. The reported phenomenology of anxiety in autism is similar to that in neuro-typical population: negative ruminative thoughts, dysphoric interoceptive experiences, narrowed attention, and negative perceptual bias [3,4].

Qigong Sensory Training (QST) is an autism treatment method that aims to address developmental neural deficits and their sequelae [5-7]. Improvements in the symptoms associated with neural developmental disorders have been demonstrated in multiple studies of QST (5-7). QST is based on principles of classical qigong, teaching parents to administer to

a child, massage, tapping and movement, most of which a neurologically mature individual could self-administer. Qigong training, irrespective of its application for internal martial arts, spiritual or personal physical development, or health/medical applications, involves developing body awareness and control through attention, movement and visualization.

QST therapists train parents to provide a carefully designed regime of daily massage and movement for their autistic child. Clinical trials have demonstrated significant improvement in digestion, social development, communications and self-regulation in many children treated with this method [5-7]. Additionally, research demonstrates that scores on parent stress tests decrease in parents who participate in administering this therapy to their child [8,9]. Study outcomes suggest that this form of therapy supports maturation of the nervous system, especially when the therapy is begun in children under 6 years of age [5-7]. Success rates in older children are somewhat lower. One of the authors of this report (MCG) is qualified to train parents to administer QST therapy.

This case report involves observations of outcomes of the use of QST in conjunction with other conventional concurrent therapies in addressing anxiety in a child with medical diagnosis of autism and severe anxiety disorder. The child, E.P., has been under the regular care of a team of paediatric autism specialists including primary paediatric care, paediatric gastroenterologist, paediatric psychiatrist and a paediatric neurologist. Diagnosis of severe anxiety was made by multiple qualified autism specialists including his psychiatrist and general paediatrician. The authors of this report were not involved in E.P.'s diagnosis.

The QST method of therapy was introduced to E.P.'s parents at their request; they were provided with verbal, written and video information [10]. Parents subsequently requested to be trained in the method. MCG visited the family home regularly, coaching the parents in their delivery of the QST massage therapy, providing massage therapy and observing progress. Between 2015 and 2019, the family has also sought out additional QST therapist support and consultation.

Correspondence to: Mardi Crane-Godreau, Geisel School of Medicine, Dartmouth, USA, Tel: 18023752969; E-mail: margaret.a.crane@dartmouth.edu

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The author (MCG) is a PhD research scientist with additional training in the QST method of autism therapy and training in Somatic Experiencing Trauma therapy (SEP). MCG was asked to begin to work with the subject (E.P.) beginning in August 2015. This work with E.P. was supplemental to other standard autism care provided by paediatricians and other specialists.

SUBJECT

The subject child, E.P., is an 11 year-old male. He, his parents and 3 siblings, live together in a traditional middle-class household in the North-eastern region of the United States. He was first diagnosed at age 2 years when his parents noticed a lack of eye contact. He has a fraternal twin who does not have any reported neurological deficits nor autism related traits. At birth, E.P. weighed 5 pounds, 6 ounces (2.4 kg). His twin weighed 6 pounds, 2 ounces (2.8 kg). Mother reports that birth was by C-section due to placenta previa. E.P. and siblings reportedly received all recommended paediatric care and vaccinations on schedule.

E.P. had bronchiolitis as an infant and has Keratosis Polaris. He is reactive to cold viruses and has been diagnosed with asthma. He was hospitalized 5 times due to asthma prior to 2015, but has had no hospitalizations since. On advice of a paediatric gastroenterologist, E.P. takes probiotics daily. He is a picky eater with a limited number of foods that he will consume.

MCG IMPRESSIONS IN AUG 2015

During visits in August 2015, E.P. was observed and a history was taken. His parents reported that E.P. was under the care of autism medical specialists. E.P.'s parents were clear in their commitment to finding ways to optimize E.P.'s wellbeing. They expressed significant concern about E.P.'s severe anxiety and language development. They reported that his anxiety was primarily associated with newness or change. The stimuli that were reported to be associated with anxiety or panic varied, ranging from seeing holiday decoration in his home, to commonly becoming anxious when leaving home. His parents also reported panic attacks in response to significant changes in weather, specifically to incoming storms. Parents reported being in dialog with E.P.'s providers regarding these and similar events.

In 2015, E.P. was hyperactive with frequent non-intelligible vocalizations that expressed heightened emotion. At this point, few words were ever articulated to me, but occasionally his parents could elicit words such as "good-bye" or "hello". E.P. showed considerable interest in building with Legos and making highly accurate models of animals, buildings and cityscapes with modelling clay. He was generally calm when engaged in these activities. However, he also spent considerable time on a tablet or computer, frequently repeatedly replaying cartoons and videos, some of which elicited heightened reactions. MCG noted by visual observation and feeling E.P.'s deep body trembling (activation) in response to specific danger-associated scenes in the videos (i.e., dinosaurs fighting or a scene with a train, whistle blaring and the crossing lights flashing, as the train approaches a road/railroad track crossing). MCG interpreted this repetitive activity and activation (trembling associated with repetitive stimulus activity) as a form of conscious self-stimulation not associated with distress, specifically not an example of anxiety.

E.P. RESPONSE TO THE 12 STEP QST MASSAGE

This is an integrated therapy that places considerable value on reinforcing the parent-child bond. Parents are encouraged to administer the therapy on a daily basis. The massage is intended to support development of the nervous system and to become a resource at times of need. It is a time of closeness and nurture. During a number of the steps, parents are instructed to make and maintain eye contact with the child. In the perspective of qigong, the various steps open and clear the pathways (channels), stimulate organ systems and balance the nervous system (body). E.P. was variously receptive to the various steps. From the onset, he would take the therapist's or parents hands and place them in areas where he apparently perceived need. When working the area around his ears, he would seek gentle pressure of the whole hand covering his ears rather than an alternative method of tapping around the ears.

Of great interest to the authors was his response to the steps involving massaging his hands. Especially in the beginning, but still somewhat apparent after 3 years of therapy, E.P. would move his lips, tongue thrust and clack his teeth in response to the massage on his fingers. No distress was apparent and this behaviour is common when delivering the prescribed massage to the hands of ASD diagnosed children; it is also described in the QST training guides and lectures. The authors hypothesize that as seen with the use of the fingers in communications through typing and sign language, that there may be brain nuclei that share sensory and muscle control signals from the fingers and the mouth, lips and tongue. E.P.'s verbal communication skills progressed beginning in the first six months, after the QST massage was initiated.

PARENTS PROVIDED QST THERAPY BEGINNING IN THE FALL OF 2015

The protocol was significantly followed for approximately 18 months and then was tapered due to resistance from E.P. While E.P. became resistant to the full protocol, he would frequently go to his parents and place their hands on his body where he wanted touch or massage therapy. He especially sought touch on his back, shoulders and abdominal areas.

In response to E.P.'s resistance to receiving full QST massage sessions, the authors provided the family with a series of short videos (each under 2 minutes) of a child of similar age to E.P., doing simple qigong movements. The videos contained music and aids to visualization. These videos were used in the home and at E.P.'s school at times of stress. Based on parent's reports, E.P. watched and occasionally mimicked the video activity. Some self-soothing activity, similar to practices shown in the videos, was reported to have developed. The parents also report that the use of the videos made a significant difference in E.P.'s ability to make transitions, for example, from home to school. Additionally they have reported a significant drop in panic attacks and an apparent increased ability for E.P. to self-soothe and self-regulate.

Reports from E.P.'s school suggest that he has made considerable progress in language, math and reading since beginning his QST therapy and support from the qigong videos. He is able to participate in group activities including making his own individual presentations. His interest in science topics, his capacity to memorize names from astronomy, and anatomy and meaningful capacity to use his computer to construct objects of interest to him, suggest a high level of intelligence. Based on observations, when he wants to communicate, E.P. is verbal and articulate. His otherwise limited use of language seems more related to his low interest in speaking, rather than a lack of capacity. Reportedly, E.P. taught himself to read.

HISTORY AND MCG IMPRESSIONS IN JANUARY 2019

E.P. attends school on a regular basis. He has a 1:1 para-educator all day at school. But largely is able to do his school work in the regular classrooms throughout the day. He currently receives speech therapy 4 times/ week and occupational therapy twice a week at school. At home he receives music therapy once a week for one hour.

In 2017 cognitive behaviour therapy (CBT) was recommended by his psychiatrist to address anxiety. E.P. had three sessions with one provider and then recently, regular sessions with another provider. An issue in providing this service is that paediatric CBT providers are not abundant in the region where he resides. His parents report not having seen change that they can attribute to CBT.

His current medications include:

Fluoxetine - 12.5 ml oid (20 mg/5ml)

Ranitidine - 10 ml oid (15 mg/ml)

Quiet Calm - 2 droppersful bid

Creatine - 1/4 tsp powder

Probiotic 75 billion - oid

Vitamin D oid (125 mcg - 5000IU)

Multivitamin with fluoride and Melatonin – 2 ml

MCG has observed a dramatic change in E.P. that is not reflected in the parent surveys. In 2015, E.P. was a hyperactive child who showed little self-regulation and was highly prone to severe anxiety attacks that frequently required intervention by both parents. These included events such as demonstrations of extreme anxiety at an approaching storm and in one instance, when traveling, jumping out of this car safety seatbelt and attempting to steer the family car off the road. In 2015 and 2016, transitions from home to school were extremely difficult with E.P. needing to be carried into school, crying and exhibiting significant anxiety. In contrast, parents report no recent panic attacks and displays of anxiety are now rare. Transitions have largely become normal activities. E.P., while still occasionally vocalizing, is largely calm and polite. His teachers also report progress and behaviours that are consistent with being able to attend school.

Parent response to surveys of E.P.'s symptoms, capacity for self-regulation and, of parent reported stress have been collected periodically since 2015 [8,9]. Changes in parent reported symptoms from 2015 to 2019 include a decrease in score in the Autism Parenting Stress Index (APSI) from 17 to 14 (a 17.6% decrease). Reporting on the QST Sense and Self-Regulation Checklist (QST-SSRC), his parents report a decrease in symptoms related to pain or aversive sensitivity to touch, from a cumulative score of 29 to 27 (a 6.9% decrease). A dramatic change was seen in scores for 'Self-Regulation-Digestion' which measures functioning of gastrointestinal system and the scores depend largely on autonomic control. Here the symptom score dropped from 10 to 6 (a 40% decrease). In contrast to these reported improvements in symptoms, E.P.'s parents report significant increased sensitivity to noise. Parents report that this necessitates the use of headphones to dampen the level of sound. Clinically relevant scores on the APSI and QST-SSRC are based on cumulative response to all factors that are evaluated; E.P.'s cumulative score overall remained within the clinically significant range on the QST-SSRC.

These clinical descriptions fail to capture the person, E.P. He is a sweet affectionate child who is amiable and popular with his school-mates, family and teachers. He is kind to his pets (3 dogs and a cat). At parties and school, he is able to interact with apparent enjoyment with other children and is universally liked. He can engage in limited social banter. In summer he loves to visit a small pond in the woods where he likes to watch the butterflies.

SIGNIFICANCE OF THIS CASE

Inherent challenges in educating and treating children and adults with autism and other neural developmental disorders include the potential of masking the disorder with medications and/or not being able to adequately access parts of the nervous system that are useful in treatments (i.e., cognitive behavioural therapy). Specifically, children and adults with diagnosis of autism may lack aspects the neural typical development that are needed to identify the source of anxiety and/or they may lack the skills associated with self-regulation and self-soothing. While the same can be seen in many neuro-typical individuals, for example those with a history of adverse childhood events have similar "low baseline of expression and reception of affective touch" [11]. Those with autistic traits may face particular challenges in identification of the source of anxiety, identifying the meaning of the sensations of anxiety and initiating and sustaining a response that is effective in addressing it. Approaches, such as qigong-based therapies and training that support development of body awareness and control, through attention, movement and visualization, take time but, are useful in autism and neural typical individuals alike.

C-tactile fibers are unmyelinated nerves that transmit the sensations of gentle affective touch. Evidence indicates that C-tactile afferent fibers "contribute to pleasant touch and provide an important sensory underpinning of social behaviour" [12]. One small pilot study of c-tactile fibers in children with autism, demonstrated a significantly lower density of these nerve fibers in study subjects. The authors postulated that a diminished capacity to sense touch might interfere with the parent-child bonding [13]. Other authors document that C-tactile fiber input modulates pain [14]. This observation

may explain why E.P. has reportedly less aversive pain over the years of treatment while at the same time acquiring other apparent benefits of QST therapy. We point to concerns that without established connections to parents and others, it is easy to imagine the difficulties in learning to communicate and to interact in socially satisfying ways. We speculate that deficits associated with C-tactile sensory input have implications in the ability to learn.

Here we report on the experience of working with one child whose family have added somatically oriented therapeutic interventions to on-going conventional autism medical care and education. They have used both the QST method of massage and movement therapy, and have employed the use of short videos that model movement, self-touch and visualization. The movement and visualizations in the videos are similar to qigong training used to support development of awareness, self-regulation in neuro-typical populations (including children and adults) and which lead to autonomic control [15-19]. The authors designed these videos, hypothesizing those children and young adults might be able to watch and/or mimic the activity that they see on the screen. In this case, parents and siblings were encouraged to also watch along with E.P. and to make watching and following along a family activity. The videos were specifically designed to address stress reduction, a sense of love and connection and development of self-confidence through inner strength. We postulate that they may have impact on other family members as well as on the subject child.

The capacity to self-regulate requires a nervous system that is able to identify the source of a stimulus, interpret its meaning and to address it in a meaningful way [20]. In contrast to cognitive therapy, body-mind oriented (somatic) therapies and educational systems employ and address needs of the whole nervous system [20]. An integrated approach using qigong-based therapies, as a supplement to standard contemporary therapies may support a more even development of the nervous system including cognitive skills. In this case report, factors such as maturation and the synergy of the various interventions, may have been at play. No conclusions can be drawn from a case report, however, we, and others, can continue to ask relevant questions and seek support from agencies and foundations which are willing to address autism and its co-morbidities.

CONSENT FOR PUBLICATION

Written informed consent for publication of this case report and for publication of any potentially identifying information was sought and obtained from the parents of the subject child.

CONFLICT OF INTEREST STATEMENT

Mardi Crane-Godreau and Peter Payne declare that teaching and consulting are sources of income. MCG and PP are co-founders and owners of a company that provides consulting, and training services.

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