CASE STUDY

Improved Quality of Life of in a Patient with Aicardi Syndrome Undergoing Chiropractic Care: A Retrospective Case Study

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Abstract

Objective: The goal of this retrospective case study is to demonstrate an increased quality of life for a patient with Aicardi syndrome undergoing subluxation based chiropractic care.

Clinical Features: An adopted four-year-old girl presented to the clinic with a diagnosis of Aicardi syndrome. Additional dysfunctions included right ear deafness, blindness, cleft palate, and sacral spina bifida vera. The patient has a bifurcated right thumb and also presented with circulatory disorders of the lower extremities, hypertension, renal dysfunction, food allergies and esophageal reflux. The chief complaint was irritability which included prolonged crying, general dislike of touch and self-injurious behavior (SIB).

Interventions and Outcomes: The patient’s total duration of care was approximately 23 months with a total of 46 visits. The patient was initially under chiropractic care using Diversified Technique, followed by Activator Technique, and lastly, SOT Cranial Technique. During care the patient increased in weight, while previously her weight remained unchanged for an entire year. She also ceased to exhibit SIB, demonstrating greater periods of calm. Also noted was a decrease in stress in the life of the caregiver.

Conclusion: Chiropractic care can be of great benefit in improving the quality of life in a patient with Aicardi syndrome and other congenital abnormalities.

Key Words: Chiropractic, Aicardi Syndrome, quality of life, self-injurious behavior, Activator, Diversified, Sacro Occipital Technique, SOT Cranial Technique, vertebral subluxation, adjustment, spinal manipulation

Introduction

Aicardi syndrome is a congenital neurodevelopmental disorder that is associated with severe cognitive as well as motor impairment. It is diagnosed based upon the dysgenesis or agenesis of the corpus colossum, chorioretinal lacunae and infantile spasms. Polymicrogyria, periventricular and subcortical heterotopias, and choroid plexi papillomas are other common neurological findings. Literature suggests presenting with two classic features plus two other major or supporting features highly favors the diagnosis. This syndrome has only been described in females and 47 XXY males, with a high mortality rate reported in male cases.

Multiple neurological abnormalities often accompany Aicardi syndrome, and include microcephaly, mental retardation,
developmental delay, intractable epilepsy, axial hypotonia and limb hypertonia with spasticity.\textsuperscript{2} In addition, craniofacial abnormalities or deformities that have been noted with Aicardi syndrome include small philtrum with upturned nasal tip, decreased angle of nasal bridge, and a prominent premaxilla.\textsuperscript{2} It is also to be noted that fused vertebrae, hemi-vertebrae, blocked vertebrae and absent ribs often lead to scoliosis and are skeletal anomalies often associated with Aicardi syndrome.\textsuperscript{2}

Behavioral Component of Developmental Disabilities:

Individuals with disorders exhibiting developmental and cognitive delays including Aicardi syndrome often demonstrate behavioral difficulties such as self-injurious behavior (SIB).\textsuperscript{7} Self injury is an unusual and often chronic form of aberrant behavior which can pose serious risk to those demonstrating this particular form of behavior.\textsuperscript{8} This includes facial tapping or hitting, head-banging, biting, eye gouging, face slapping, hair pulling, jaw popping or other behavior that invokes harm on the individual.\textsuperscript{9} Each individual presents differently and may demonstrate various levels of severity. It has been demonstrated that those demonstrating SIB have a lower quality of life.\textsuperscript{9}

There have been several studies that have shown people undergoing chiropractic care have improved quality of life.\textsuperscript{10-13} There is little to no literature demonstrating a correlative or causative relationship regarding increased quality of life with chiropractic care and Aicardi syndrome; further studies should be conducted in attempts to underline the relationship between these variables.

Case Report

Patient History

The patient is a four-year-old female who was adopted at birth. Due to her adoption, little is known about her biological mother other than she was a 38-year-old non-registered immigrant at time of birth, and had gestational diabetes. The patient was born via cesarean section without complications.

The patient was born with anophthalmia of the left eye and microophthalmia of the right eye. The patient has a right hand deformity in which the thumb divides into two digits. The patient also presented with renal cyst, eczema, cleft palate, and spina bifida vera. Following birth, the patient was placed in intensive care for the first six weeks of life during which time a sacral spina bifida vera was surgically repaired. The cleft palate was surgically repaired at nine months of age.

At approximately three years of age the patient began having seizures. Prior to the first epileptic episode, the patient demonstrated mild spastic behavior on two separate occasions, but not with any predictable timing or frequency. The patient then experienced a more severe epileptic episode, after which time the patient began having multiple spastic episodes throughout the day. They would typically occur just after waking. The patient was taken to the emergency room at which time a neurological consult was recommended.

An electroencephalogram (EEG) was performed and a diagnosis of infantile spasms as well as Aicardi syndrome was given by the attending medical doctor. The patient was placed on Topomate\textsuperscript{®} (25mg/day), which is an FDA approved medication for general epilepsy. The patient’s symptoms improved and she was later placed on Acthgar\textsuperscript{®} gel injections (a steroid medication) for six weeks. The seizure activity drastically dropped off with only one other epileptic episode occurring since being placed on anti-seizure medications.

The patient developed acid reflux after discontinuation of Acthgar\textsuperscript{®} gel at which time the patient’s medical doctor prescribed Zantac\textsuperscript{®}, a proton pump inhibitor designed to prevent esophageal acid reflux. According to the caregiver, the drug was ineffective, therefore the medication was discontinued and acid reflux persisted. Additional medical concerns included history of hypertension, which was associated with a hypoplastic, abnormal functioning right kidney diagnosed by her nephrologist.

Activities of Daily Living:

The patient is unable to feed herself without assistance and so the caregiver places a tray in front of the patient to indicate the presence of food, then places the food on a spoon at which time the patient is able to grasp the spoon and place the food into her mouth. The patient has never grabbed food by hand and then placed it into her mouth without assistance. All food is ground into a puree consistency as the patient is unable to masticate, but is able to swallow with occasional difficulty. In order to assist in drinking, a modified cup with two handles and a nipple is placed in front of her and the word “cup” is said loudly; the patient then responds by grasping the cup and drinking.

The patient has never crawled, cannot walk, but can move across a room by lying on her back and wigglng her torso in a “crabwalk” fashion. She is capable of grasping objects, grabs, pulls and pushes, especially when expressing dislike. She is able to sit up and hold her head up and remain in an upright position if placed by the caregiver, but cannot pull herself up to sit. She expresses left-handedness and tends to favor her left side. The patient is able to stand with support against an object in front of her, and uses a “walker-type” apparatus to help support her body weight.

Communication and Behavior

The patient uses mostly non-verbal communication to express likes and dislikes. She can reportedly understand language and responds by using her own body language. The patient can also recognize sound, touch, and smell. She can say the words “up”, “cup”, “eat”, “mama” and “shah” (the word for her sister). She can use sign language for “all finished” and “drink.”

Her caregiver described her behavior as somewhat challenging as she often appeared agitated or irritable with prolonged periods of crying and engaging in SIB; hitting herself in the face and head, as well as aggressive facial rubbing thus affecting her quality of life.\textsuperscript{9} Caregivers undergo additional stress, coping with maladaptive behaviors of special needs children compared to caregivers of non-special needs children, which often leads to a decreased quality of life for the
Examination

The patient presented to the clinic for chiropractic care with the chief complaints of prolonged crying, irritability, general dislike of touch and SIB, consisting of hitting herself in the face and in the head, as well as aggressive facial rubbing.

At the time of the physical examination, the patient appeared irritable and presented with multiple rashes on the face and extremities, which was later diagnosed as eczema. Vital signs were taken, with the exception of blood pressure. Her pulse was 92 beats per minute. Her temperature (axillary) was 97.6 degrees Fahrenheit. The patient weighed approximately 20 pounds and measured 38 inches in length. Head and chest measurements were also taken. Head circumference was measured at 41 centimeters and chest circumference was measured at 49 centimeters.

A non-cooperative patient prevented the performance of a cranial nerve exam. Pallesthesia was performed with no reaction to a 128 hertz tuning fork when placed on extremities (lower extremity, patella, fibular head, lateral/medial malleoli, and the styloid process of the fifth metatarsal base; upper extremity, acromioclavicular joint, olecranon process, and the radial and ulnar styloid processes). Patellar and achilles deep tendon reflexes were performed; a biceps reflex test was not performed. Patellar deep tendon reflexes were 2+ bilaterally. Achilles deep tendon reflexes were 1+ on the right and absent on the left, using the Wexler scale.

Spasticity and hypertonicity of the left paraspinous musculature including the erector spinae group: iliocostalis, longissimus and spinalis, were noted on the left with rib humping also present. A right convex scoliosis from T2-T9 and a left convex scoliosis from T10-L4 were present, with the apices T5 and L1 respectively. Hypertonicity of the cervical paraspinus musculature were noted bilaterally, including splenius capitis, levator scapulae, longissimus cervicis and suboccipital musculature including rectus capitis posterior major, rectus capitis posterior minor, obliquus capitis superior and inferior. Left lateral head tilt and right rotation were noted with global restrictions in cervical ranges of motion, mainly right lateral flexion, pure flexion, and left rotation. An anatomical leg length discrepancy was present with the right leg measuring 39.5 centimeters and the left leg measuring 40.5 centimeters.

Several cranial asymmetries and motion abnormalities were observed. Cranial asymmetries included flattened frontal bone, right sunken sphenoid, otherwise described as concavity of the right sphenoid. The patient also demonstrated concavity of the zygomatic arch as well as bulging of the right parietal bone. Cranial fixations and malpositions included fixation of the left sphenoid into flexion, right temporal external rotation and right occipital inferior torsion. Subluxations of the atlas and occiput were also noted.

Intervention

The patient initially began receiving chiropractic adjustments in the form of Diversified Technique. Diversified Technique is described as “[t]he basic chiropractic analysis [consisting] of manual palpation of the bony elements of the spine, manual assessment of the motion of the spine and individual vertebrae, and palpation of the numerous muscles which attach and control spine and vertebral motion.”

In addition to chiropractic intervention, the patient was also undergoing occupational therapy which after assessment mainly focused on attempting to build her sign language vocabulary, using a walker with wheels and self-feeding with her fingers as well as using a cup without handles.

The first chiropractic adjustment consisted of an occipital lift in which the patient was lying supine on the adjusting table. The fleshy portion of the intern’s finger pads were placed just under the occipital rim and approximately one inch inferior to the superior nuchal line, then slight inferior to superior traction was applied to restore proper motion and kinematics between the occiput and atlas. One week following the first adjustment, the caregiver reported the patient was much less irritable throughout the week and was more receptive to therapeutic touch. The following visit consisted of an occipital lift (detailed above) as well as an adjustment of the sacrum. When adjusting the sacrum, a fingertip contact was made with the patient lying prone on the chiropractic table, then the intern used the fleshy portion of both fingertips overlapping each other, contacting the right posterior superior aspect of the sacrum, making a gentle high velocity, low amplitude thrust in a posterior to anterior, and superior to inferior line of drive.

After the third adjustment consisting of the previously mentioned protocol, the patient exhibited a decrease in primitive posturing as well as an increase in response to caregiver touch. On the seventh visit the patient presented with an exacerbation of symptoms, especially irritability and resistance to touch. Subsequently, on the following visit, the patient was calmer and more receptive to the adjustment. The patient continued to be adjusted via Diversified Technique for a total of 22 visits over a one year span. There were occasional gaps in care consisting of missed appointments which were then rescheduled to a later date.

There was a two month gap in care in which the patient was out of town. During this gap the caregiver reported an increase in irritability and increased episodes of SIB, as described earlier.

The patient was then adjusted via Activator Technique being scheduled to be seen once a week. Activator Technique involves the use of a handheld spring-loaded instrument that when used, delivers a predictable, calculated thrust to make the adjustment.

There are four different settings on the Activator IV that allow for an increasing amount of output force to be used with each setting, ranging from 16 lbs to 38 lbs. A total of six adjustments were given via Activator Technique, focusing on the occiput and sacral subluxations. The occipital adjustment was made by placing the rubber tip of the activator against the posterior inferior margin of the occiput of the prone patient. The number one setting was used, delivering a predictable amount of force into the bony and soft tissues, in an inferior to

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superior, and posterior to anterior line of drive. The sacral adjustment was made by placing the rubber tip of the activator against the posterior superior aspect of the sacrum. The number one setting was used, and the adjustment was made using a posterior to anterior and superior to inferior line of drive. The patient showed continual improvement while under care in the form of decreased irritability, but was still exhibiting SIB. She did however display an increase in receptiveness to touch.

After six adjustments under Activator Technique, Sacro Occipital Technique (SOT) specifically SOT Cranial Technique was implemented. SOT Cranial Technique is a method of care whose premise is that it is possible to affect the physiology of the body by applying specific force/s to the bones of the skull and related structures. Due to substantial cranial asymmetries and perceived cranial dysfunctions that presented with this particular patient, it was felt that this particular approach would be well suited to the patient.

To correct flexion malposition of the left sphenoid, both thumb pads were placed on the greater wing of the sphenoid bone bilaterally and the palmar pads of digits 2-5 were placed along the inferior ridge of the occiput. The right hand maintained its stabilizing position over the right portion of the cranium as a superior and posterior force, or stress, with the left thumb was placed on the greater wing of the sphenoid on the left. This movement was performed while the patient was in the exhalation phase of breathing.

To correct right temporal external rotation, the left palm was placed transversely across the width of the entire cranium to stabilize it. The patient’s right temporal bone was contacted by the intern’s right thenar pad, with the fleshy portion of the right fingertips contacting the postero-lateral portion of the right mastoid body and process, while stressing the temporal bone anterior and inferior. This movement was performed while the patient was in the exhalation phase of breathing.

To correct right occipital inferior torsion, the palmar surface of the right hand was placed upon the supine-lying patient’s frontal bone with 2nd and 3rd, and 4th and 5th digits straddling the maxilla. The left hand was positioned with the palm over the occiput and the fingers directed caudally. While the patient inhaled, the doctor directed an inferior to superior and counter-clockwise stress with his inferior hand directed towards the right inferior portion of the patient’s occiput.

To achieve cerebrospinal fluid (CSF) balancing at the “occipital bowl,” the doctor placed both hands along the inferior nuchal line of the supine patient using an extremely light contact, waiting to feel bilateral synchronization and symmetry of pulsations to indicate proper CSF flow. The contact was held during both the inhalation and exhalation phase of respiration.

**Quality of Life Survey**

A quality of life survey was created to be filled out by the primary caregiver in order to better assess quality of life for this patient. Other quality of life surveys exist in literature but because of this patient’s severe motor and cognitive impairments, it was felt that these surveys did not provide proper content to assess quality of life for this particular patient.

Ideally, the form would be completed both prior to the onset of care and again at the conclusion of care, then the scores would be compared. Because this case study was not foreseen at the onset of care, the caregiver filled out both surveys at the conclusion of care. She was asked to fill out both forms honestly and to the best of her ability to represent the patient’s status as well as her own status both prior to and after chiropractic care.

**Outcome**

The patient received a total of 46 adjustments in just under a two-year period. During this time the patient showed improvements in several areas of functioning including a complete extinction of SIB.

After the first visit the caregiver reported that the patient was far less irritable and was more receptive to touch. By the third visit the patient began to show decreased primitive posturing and continued to be more receptive to touch. The caregiver had previously reported that the patient’s weight had been relatively stagnant for an entire year. Within a four month period while under chiropractic care, the patient increased two clothing sizes and gained nearly two pounds. After the 29th visit the caregiver reported that the patient had less difficulty swallowing when eating.

It was previously discussed in the case report that self-injurious behavior leads to decreased quality of life. While under chiropractic care the patient ceased to exhibit SIB therefore adding to her quality of life. According to the survey the caregiver also reported an increased quality of life as a result of chiropractic care for her child. (See Figure A and Figure B)

While more studies are needed to fully understand the role of chiropractic on those with developmental disabilities, this study supports an outcome of increased quality of life associated with chiropractic intervention and Aicardi syndrome.

**Discussion**

**Quality of Life**

There is no unified consensus in the literature as to the definition of *quality of life*, however, Bowling gives the definition: “Quality of life is a concept representing individual responses to the physical, mental and social effects of illness on daily living which influences the extent to which personal satisfaction with life circumstances can be achieved. It encompasses more than adequate physical well-being, it includes perceptions of well-being, a basic level of satisfaction and a general sense of self-worth.”

The eleven question survey that was created and implemented for this case study assesses four key domains which consist of family interaction, emotional well-being of the caregiver, emotional well-being of the patient, and physical well-being of the patient. It should be mentioned that the quality of life
survey implemented in this study has not been evaluated for reliability or validity to assess whether or not it can accurately measure changes in quality of life.

As this survey represents a perception of the patient’s health provided by the caregiver, answers may have been adapted according to expected patient benefit, current mood or other factor. The caregiver was instructed to answer all questions honestly and to the best of her ability. Nonetheless, the survey implemented can provide some insight as to the changes in quality of life that took place over the course of care. (See Figure A and Figure B)

**Diversified Technique**

Diversified Technique is a commonly taught adjusting technique and implements several different sources. It consists of adjustments of the spinal column and the extremities. No specific analytic system is used. Instead, Diversified Technique calls upon the assessment of normal biomechanics, as well as static and motion palpation of a joint and related soft tissue structures to discern the need for manual adjusting, in an attempt to create or restore motion in a particular joint. This technique involves the use of a high-velocity, low-amplitude thrust with a line of drive or directional force specific to each finding, to correct perceived joint dysfunction. More research is needed to fully understand the role of Diversified Technique and its effect on human physiology.

**Korr’s Facilitation Hypothesis**

Korr suggested that when muscles are subjected to abnormal stress or strain, mechanoreceptors located in the muscle begin to become activated. Abnormal positioning of a vertebrae could possibly affect the tone of the muscles related to it and cause increased firing of proprioceptors in said muscles. In the case of this patient, the suboccipital muscles were affected which make their origin and insertion to the cervical vertebrae and play an important role in postural processes, head movements and eye coordination. As a result, increased nociception and decreased proprioception into the central nervous system can occur.

This increased nociceptive input might explain behaviors of prolonged crying, irritability and SIB that were being demonstrated by the patient. However this statement is purely speculative until further studies can be conducted to confirm the relationships between these variables.

Proprioceptive information is facilitated by second-order neurons in the spinal cord which can have affects on the proprioceptive information that is being received and can decrease the firing threshold of these neurons, which in turn increases their sensitivity.

When second-order neurons are facilitated they become hypersensitive to impulses that could be arriving from any source in the body, visceral or somatic. In the spinal cord, second-order neurons synapse with lateral horn cells as well as anterior horns cells, which are part of the sympathetic nervous system. Continuous irritation of the lateral horn cells, as a result of overstimulation via abnormally functioning musculature from malpositioned vertebrae, could cause lateral horn cells in the spinal cord to be facilitated or hypersensitive. This facilitated or hyper-irritable sympathetic nervous system is considered by Korr to be a major contributing factor in the etiology of musculoskeletal dysfunction and visceral organ disease. Cardiovascular, gastrointestinal and certain musculoskeletal disorders have been associated with overstimulation of the sympathetic nervous system.

Chiropractic adjustments restore proper proprioception by restoring proper vertebral motion and position, leading to decreased stretching or tension seen in related cervical musculature. This could potentially lead to a decrease in overstimulation of the lateral horn cells having a calming influence on the sympathetic nervous system. It is reasonable to hypothesize that a decrease in manifestation of visceral or musculoskeletal conditions would be seen in a properly functioning nervous system.

**Activator Technique**

According to Menke and Fuhr, Activator Methods Chiropractic Technique is based on a dynamic approach to spinal and somatic dysfunction in which areas of spinal and extremity dysfunction are identified by specific movements that are performed by the patient, as well as identification and observation of functional leg length change that occurs with areas of dysfunction. Areas of dysfunction are corrected with a mechanical instrument designed to deliver a pre-set force to bony and soft tissues.

A study by Nguwen concluded that the prone extended leg length inequality or functional leg length inequality that is used by Activator Methods to detect areas of dysfunction in the spine and extremities had good inter-examiner reliability. This study supports that it is possible to detect areas of neurological dysfunction by isolating spinal segments and observing functional leg length change. Leg length inequality is measured by looking at the heels of the patient’s feet in the prone position. When the person first lies prone on the table, the side of the short leg is termed the “pelvic deficient” or PD side. The patient is instructed to perform a specific movement or isolation test and the examiner looks for a functional leg length change. A specific isolation test correlates with a specific area of spinal dysfunction. For example, instructing the patient to place the hand that correlates with the PD side above their head while lying in the prone position isolates the T12 spinal segment. If there is an overstimulation of mechanoreceptors from a malpositioned vertebrae present, in this example T12, a functional leg length change producing an apparent short leg occurs and the area of dysfunction (subluxation) is corrected with the Activator instrument. It was found by Keller et al. that the Activator instrument is effective for the correction of dysfunction in the spine and extremities.

Activator Technique is taught in the majority of U.S. Chiropractic colleges and it is estimated that approximately 45,000 Doctors of Chiropractic use this technique worldwide. In fact, recent surveys from the National Board of Chiropractic Examiners states that Activator Technique is one of the two most widely used chiropractic techniques in the United States. Further research is needed to fully understand...
the role of Activator Technique and its effects on human physiology.

**SOT Cranial Technique:**

In SOT Cranial Technique, pressure in specific vectors are applied to various bones of the skull to affect physiology. Studies have demonstrated that there is cranial bone movement in humans and that it continues into adulthood. It was demonstrated by Pick in an MRI study that pressure to maxilla and bregma, changes the shape of brain tissues including the fornix, by four millimeters and the corpus callosum, by five millimeters. This study shows that it is possible to affect brain structure and possibly brain physiology by applying forces to the bones of the skull.

According to Retzlaff, “Cranial dural membranes form the walls of the cranial venous sinuses, and help maintain the position of the cerebellum, cerebrum and spinal cord as well as help provide some support to the cranial capsular matrix by passing through the sutures to become external periosteum of the cranium.” The connection of muscles such as the rectus capitis posterior minor, spinal ligaments to the dura, as well as the dentate ligament connecting the spinal cord to the dura, all indicate a relationship between spinal dynamics and its perpetuation into the meningeal fascial tissue.

The cranial nerves also carry dural sleeves with them for an extended distance; therefore abnormal meningeal tension could be transmitted to a nerve and therefore affect its function. Tension encountered anywhere along the meninges could possibly be transmitted to the cranial nerves. This is because the peripheral and the central nervous systems are a continuous tissue tract. The neuropathies that could ensue from cranial bone dysfunction are hypothesized to be both motor and/or sensory, and their severity depends on the amount of compression as well irritation to nervous tissue.

As some aspects of cranial related technique are still considered controversial or unproven, further study is needed to fully understand the relationship/s of cranial bones and their related structures as well as the role of cranial therapy in the form of SOT Cranial Technique on human physiology.

**Conclusion**

This retrospective case study followed a four-year-old girl with Aicardi syndrome and other congenital anomalies and changes that occurred in the quality of life of both her and her caregiver as a result of chiropractic care.

While under chiropractic care the patient ceased to exhibit SIB in the form of hitting herself in the face and head, and aggressive facial rubbing. The patient also became more receptive to touch, experienced decreased irritability and made significant weight gains within four months of care after a year of stagnant weight. Overall the patient demonstrated an increased quality of life. This statement is supported by the fact that the patient no longer exhibits SIB which is directly associated with a decreased quality of life. The quality of life survey also suggests that the patient as well as the caregiver demonstrated an increased quality of life while the patient was undergoing chiropractic care.

Overall there is an extremely limited amount of research when it comes to those with developmental disabilities, including Aicardi syndrome, and chiropractic care. Limitations to this study include the fact that it focuses primarily on one individual as well as the fact that the survey lacks an evaluation of its validity and reliability. This study does however add to the growing body of literature that suggests chiropractic care does indeed enhance overall quality of life.

**References**


FIGURE A

Quality of Life Survey

Please answer the following questions to the best of your ability. Please answer all questions truthfully. The following survey is to be completed by the primary caregiver(s). This survey is, ideally, to be completed before and after the onset of chiropractic care. *This survey represents the patient and caregiver before chiropractic intervention.*

**Family Interactions:**

1. As a parent or caregiver I feel alone in managing my disability-related child. Please circle the number that you feel is appropriate. 0 represents I feel completely alone and have no support, while 5 represents I feel I have people to help and very good support.

   0 1 2 3 4 5

2. As a parent or caregiver I feel well equipped to manage my disability-related child's needs. Please circle the number your feel is appropriate. 0 represents I am ill-equipped to manage my disability related child’s needs, while 5 represents I am well-equipped to manage my disability-related child’s needs.

   0 1 2 3 4 5

3. As a parent or caregiver I feel my disability-related child receives appropriate therapeutic attention. Please circle the number you feel is appropriate. 0 represents I feel my disability-related child does not receive appropriate therapeutic attention, while 5 represents I feel my disability-related child receives appropriate therapeutic attention.

   0 1 2 3 4 5

**Emotional Well-Being of Parent:**

4. As a parent or caregiver I experience daily stress because of my disability-related child's needs. Please circle the number you feel is appropriate. 0 represents I feel no daily stress because of my disability-related child’s needs, while 5 represents I feel an extreme amount of daily stress because of my disability-related child’s needs.

   0 1 2 3 4 5

5. I feel the services that are provided to my disability-related child decrease or improve my daily stress. Please circle the number you feel is appropriate. 0 represents the services provided to my disability-related child do not decrease or improve my daily stress levels at all, while 5 represents the services that are provided to my disability-related child decrease or improve my daily stress a great deal.

   0 1 2 3 4 5

**Emotional Well-Being of Patient:**

6. The disability-related child is easily frustrated with trying to perform simple and limited activities. Please circle the number your feel is appropriate. 0 represents that my disability-related child is not easily frustrated with trying to perform simple and limited activities, while 5 represents that my disability-related child gets extremely frustrated with trying to perform simple and limited activities.

   0 1 2 3 4 5
7. The disability-related child responds to frustration with self-injurious behaviors (hitting/slapping/excessively rubbing) head or face. Please circle the number you feel is appropriate. 0 represents that my disability-related child does not exhibit any form of self-injurious behavior, while 5 represents that my disability-related child exhibits excessive self-injurious behavior.

0 1 2 3 4 5

8. The disability-related child performs self-injurious behaviors daily that are not necessarily related to frustrating events. Please circle the number your feel is appropriate. 0 represents that my disability-related child does not exhibit any form of self-injurious behavior, while 5 represents that my disability-related child exhibits excessive self-injurious behavior.

0 1 2 3 4 5

**Physical Well-Being of Patient:**

9. The disability-related child is receptive to loving touch. 0 represents that my disability-related child is not receptive to loving touch at all, while 5 represents that my disability-related child is very receptive to loving touch.

0 1 2 3 4 5

10. The disability-related child is receptive to therapeutic touch. Please circle the number you feel is appropriate. 0 represents that my disability-related child is not receptive to therapeutic touch at all, while 5 represents that my disability-related child is very receptive to therapeutic touch.

0 1 2 3 4 5

11. Services that are provided to my disability-related child have decreased the incidence and frequency of self-injurious behavior. Please circle the number you feel is appropriate. 0 represents the services provided to my disability-related child have not at all decreased the incidence and frequency of self-injurious behavior, while 5 represents that the services provided to my disability-related child have decreased the incidence and frequency of self-injurious behavior a great deal.

0 1 2 3 4 5
FIGURE B

Quality of Life Survey

Please answer the following questions to the best of your ability. Please answer all questions truthfully. The following survey is to be completed by the primary caregiver(s). This survey is, ideally, to be completed before and after the onset of chiropractic care.

This survey represents the patient and caregiver after chiropractic intervention.

Family Interactions:

1. As a parent or caregiver I feel alone in managing my disability-related child. Please circle the number that you feel is appropriate. 0 represents I feel completely alone and have no support, while 5 represents I feel I have people to help and very good support.

   0 1 2 3 4 5

2. As a parent or caregiver I feel well equipped to manage my disability-related child's needs. Please circle the number you feel is appropriate. 0 represents I am ill-equipped to manage my disability-related child’s needs, while 5 represents I am well-equipped to manage my disability-related child’s needs.

   0 1 2 3 4 5

3. As a parent or caregiver I feel my disability-related child receives appropriate therapeutic attention. Please circle the number you feel is appropriate. 0 represents I feel my disability-related child does not receive appropriate therapeutic attention, while 5 represents I feel my disability-related child receives appropriate therapeutic attention.

   0 1 2 3 4 5

Emotional Well-Being of Parent:

4. As a parent or caregiver I experience daily stress because of my disability-related child's needs. Please circle the number you feel is appropriate. 0 represents I feel no daily stress because of my disability-related child’s needs, while 5 represents I feel an extreme amount of daily stress because of my disability-related child’s needs.

   0 1 2 3 4 5

5. I feel the services that are provided to my disability-related child decrease or improve my daily stress. Please circle the number you feel is appropriate. 0 represents the services provided to my disability-related child do not decrease or improve my daily stress levels at all, while 5 represents the services that are provided to my disability-related child decrease or improve my daily stress a great deal.

   0 1 2 3 4 5

Emotional Well-Being of Patient:

6. The disability-related child is easily frustrated with trying to perform simple and limited activities. Please circle the number you feel is appropriate. 0 represents that my disability-related child is not easily frustrated with trying to perform simple and limited activities, while 5 represents that my disability-related child gets extremely frustrated with trying to perform simple and limited activities.

   0 1 2 3 4 5
7. The disability-related child responds to frustration with self-injurious behaviors (hitting/slapping/excessively rubbing) head or face. Please circle the number you feel is appropriate. 0 represents that my disability-related child does not exhibit any form of self-injurious behavior, while 5 represents that my disability-related child exhibits excessive self-injurious behavior.

   0  1  2  3  4  5

8. The disability-related child performs self-injurious behaviors daily that are not necessarily related to frustrating events. Please circle the number your feel is appropriate. 0 represents that my disability-related child does not exhibit any form of self-injurious behavior, while 5 represents that my disability-related child exhibits excessive self-injurious behavior.

   0  1  2  3  4  5

*Physical Well-Being of Patient:*

9. The disability-related child is receptive to loving touch. 0 represents that my disability-related child is not receptive to loving touch at all, while 5 represents that my disability-related child is very receptive to loving touch.

   0  1  2  3  4  5

10. The disability-related child is receptive to therapeutic touch. Please circle the number you feel is appropriate. 0 represents that my disability-related child is not receptive to therapeutic touch at all, while 5 represents that my disability-related child is very receptive to therapeutic touch.

   0  1  2  3  4  5

11. Services that are provided to my disability-related child have decreased the incidence and frequency of self-injurious behavior. Please circle the number you feel is appropriate. 0 represents the services provided to my disability-related child have not at all decreased the incidence and frequency of self-injurious behavior, while 5 represents that the services provided to my disability-related child have decreased the incidence and frequency of self-injurious behavior a great deal.

   0  1  2  3  4  5