

THE ADAPTATION AND ASSESSMENT OF SOCIAL VALIDITY OF A FORM OF TAI
CHI VIDEO FOR CHILDREN WITH CHARGE SYNDROME

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This project is dedicated to
my family and all the CHARGE families
I have had the blessing to work with, for they
have shaped me as a professional and human being.

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ABSTRACT

THE ADAPTATION AND ASSESSMENT OF SOCIAL VALIDITY OF A FORM OF TAI CHI VIDEO FOR CHILDREN WITH CHARGE SYNDROME

by Maria Alejandra Ramirez

CHARGE syndrome is a genetic condition caused in most cases by a mutation of the *CHD7* gene. Individuals with CHARGE syndrome are often born with visual, vestibular, neurological, musculoskeletal abnormalities and multi-sensory impairment which may lead to issues with self-regulation. These individuals may experience executive dysfunction; challenging behavior; and difficulties with communication, swallowing, sleep, balance, and mobility. Although the literature on CHARGE describes these issues, there is limited research on therapies or interventions that may improve the behavioral functioning of these children. A specific therapy that has been used with children with CHARGE, but not yet evaluated, is that of Fun Chi, an adapted form of Tai Chi (Barrey-Grassick, 2011). The purpose of the current study was to assess the social validity of a video delivery of Fun Chi to children with CHARGE syndrome. It is important to assess the social validity of this Fun Chi video so that, if effective as a form of delivery of the intervention, it can be used in subsequent research where the effects of Fun Chi practice on problems experienced by children with CHARGE can be measured.

In the current study, families received the Intent to Participate Form, Parent Treatment Integrity Checklist, and the Fun Chi video, which they used with their child three times per week for six weeks. The Parent Opinion Questionnaire was completed via SurveyMonkey® by parents at the end of weeks two, four, and six. Three of the five families recorded the first and last Fun Chi sessions and one of the five families recorded all but one session. The primary researcher observed and recorded four of the five families practicing Fun Chi in their home, the primary

researcher and research assistant independently completed the Researcher Treatment Integrity Observation Checklist and inter-rater reliability was computed.

Three of the five parents found the Fun Chi video helped them perform Fun Chi with their child during the duration of the study, all but one parent consistently found the video was easy and clear to use and that the goals of the video were clear and acceptable, and parents suggested specific visual and auditory aspects that should be improved in the development of the next Fun Chi video. Four of the five parents noted improvements in their child in the areas of: relaxation during and after Fun Chi, decrease in sleep issues, improved balance, increased ability to deal with frustration, and an increase in ability to respond to situations that were previously difficult for child to cope with. Visual analysis of the parent recorded Fun Chi session showed that these four children improved in their ability to perform several forms independently; some children also improved in their range of motion and balance.

This study highlighted the importance of sensory considerations in addition to physical considerations when adapting therapies or interventions such as Tai Chi to children with CHARGE syndrome. In addition, it provided valuable data about specific components parents perceive to be important in such adaptations. Incorporating parent suggestions will make this practice more socially valid and make the assessment of the effects of Fun Chi in children with CHARGE more meaningful and accurate.

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CHAPTER I

INTRODUCTION

Statement of the Problem

CHARGE syndrome is a genetic condition caused in most cases by a mutation of the *CHD7* gene during early embryonic development. CHARGE is an acronym that stands for what were assumed in 1981 to be the main affected areas in the syndrome. C stands for coloboma of the eye, H stands for heart, A stands for atresia of the choanae, R stands for retardation of growth and development, G stands for genitourinary, and E stands for ear anomalies and hearing loss (Pagon, Graham, Zonana, & Yong, 1981). Individuals with CHARGE syndrome often have complications including anatomical anomalies that may interfere with typical development. Frequently they may also experience high degrees of executive dysfunction, communication difficulties, swallowing difficulties, and visual, vestibular, musculoskeletal abnormalities that often lead to poor balance and mobility. They are also usually multi-sensory impaired, and today CHARGE is the leading cause of congenital deafblindness (The National Consortium on Deaf-Blindness, 2009). Challenging behaviors are also often observed in children with CHARGE (Hartshorne & Cypher, 2004) and can be understood as behavioral, emotional, cognitive, and physiological regulatory difficulties experienced by individuals with CHARGE syndrome. Much research on CHARGE has led to a better understanding of the difficulties and challenges faced by these individuals and their families. However, little literature has explored therapies or interventions that may increase their functioning and ameliorate these self-regulatory difficulties.

A holistic and encompassing therapy that has been practiced for over three centuries to promote physiological and psychological well-being is the ancient art of Tai-Chi. In the beginning this practice was used as a means for self-defense but has since evolved to become a

vehicle of relaxation through integration of the mind and the body via a series of circular movements, stretches, deep breathing, and mental awareness (Li, Hong & Chan, 2001). According to Metzger and Zhou (1996) Tai Chi requires a balanced integration of external movements and internal mental imagery. Tai Chi has been practiced in China for over 300 years and more recently has become a practice adopted by intrigued practitioners in the west who have identified many positive psychological and physiological outcomes (Wolf, Coogler, & Xu, 1997).

Individuals with CHARGE syndrome, given their various challenges may benefit from a practice such as Tai Chi to improve the integration and functioning of processes, such as sensory integration, balance, sleep and behavior. In fact, since 2009, an adapted form of Tai Chi called Fun Chi has been practiced by a Tai Chi practitioner and DeafBlind educator in Perth, Australia with students who are deafblind and have sensory issues (Barrey-Grassick, 2011). However, documentation of the effects and efficacy of this adapted form has not yet been provided.

Statement of Purpose

While Tai Chi may be adapted for children with disabilities such as CHARGE syndrome in order to study the effects of Tai Chi on this population, it is necessary to provide Tai Chi instruction to these children. Children with CHARGE are widely dispersed, thus the only practical way to accomplish this is to use video instruction. The purpose of this study is to develop and assess the utility and social validity of a video on an adapted form of Tai Chi for children with CHARGE Syndrome.

Research Questions

What is the social validity of a video demonstrating an adapted form of Tai Chi to parents and children with CHARGE syndrome? Specific questions addressed are the following:

1. Does the video help parents use Tai Chi with their child?
2. Do parents find the video easy and clear to use?
3. Do parents find the goals of the video acceptable and clear?
4. Are the procedures exemplified in the video clear and acceptable?
5. Are the observable effects of the repeated practice of the video positive?

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

The following review will explore Tai Chi, its positive effects, consideration for adapting Tai Chi for individuals with disabilities, and the importance of assessing the social validity of an adapted form of Tai Chi (Fun Chi).

The Two Pillars of Tai Chi: Neurological and Physiological Components

Tai Chi is a practice which in its most basic form consists of 24 integrated circular movements, deep breathing and mental concentration (Li, Hong, & Chan, 2001). The origin of Tai Chi dates back to the Ming Dynasty, between the 1300's and 1600's. It was originally utilized as a means of physical fitness and self-defense, but it has evolved into a practice involving both a mental/meditative aspect as well as a physical component consisting of relaxed and balanced physical movements (Li, Hong, & Chan, 2001).

This practice has been observed to provide many health benefits, including improvements in sleep (Irwin, Olmstead, Sarosh, & Motivala, 2008), immune function (Sun, Xu, Xia, 1989., Sun, Xu, Zhu, 1990., Irwin, Pike, Cole, Oxman, 2003), and balance (Gatts, & Woollcott, 2005., Tsang, Hui-Chan, 2004., Tsang, Hui-Chan, 2008., Xian Li, Qing Xu, & Hong, 2008., Lephart, Pincivero, Giraldo, Fu, 1997., Gardner, Martin & Jessell, 2000). Tai Chi can best be understood as a two-pronged practice. The first aspect is the neurological component, often referred to in the literature as the mental/cognitive component. This entails meditation, relaxation, and concentration. The second aspect is the physiological component consisting of the practice of systematic and fluid movements.

Neurological: Mental/Cognitive Component of Tai Chi

Tai Chi is a practice that leads the mind to a relaxed meditative state through soft and repetitive movements. Researchers have looked at the effects of meditation on brain activity. This research has revealed the inferior frontal, fusiform, occipital and postcentral gyri areas of the brain to be activated during the process of meditation (Lou et al, 1999). Other studies have observed increased blood flow to the frontal cortex (Herzog, et al, 1990., Jerving, Anana, Biedeback, & Fernando, 1996) and increased frontal activity (Banquet, 1973., Wallace, Benson, & Wilson, 1971). Lazar, et al. (2000) performed brain imaging of neural activity using functional magnetic resonance imaging (fMRI), to determine whether the attention and arousal areas of the brain would be activated during the process of meditation. In the sample of five experienced Tai Chi practitioners, the researchers found that this form of meditation does activate neural structures. Specific areas that were activated were the frontal and parietal cortex, hippocampus, and mid brain. These areas are believed to be involved in executive functioning, memory, learning, movement and emotion.

Physiological Component of Tai Chi

As noted previously Tai Chi can be understood as a two-pronged practice, involving both a neurological component and a physical component. Metzgar and Zhou (1996) reinforce this point by stating that the practice of Tai Chi consists of both relaxation, such as that observed in meditation, and repeated sequences of circular movements. There is considerable literature on the benefits of relaxation and the ability to self-instruct to relax would be a form of self-regulation. An interesting review by Ungerleider, Doyon, and Karni (2002) examined the development of a repeated motor task and its effects on neural activation, which while it was not

Tai Chi, may provide some evidence in support of the repeated sequence of movements which constitute Tai Chi.

The underlying mechanisms and processes that facilitate and lead to the acquisition of motor skills were explored by Ungerleider et al. (2002). They explained that “motor skill refers to the process by which movements, produced either alone or in a sequence, come to be performed effortlessly through repeated practice” (p. 554). This process requires both skill acquisition or learning and motor adaptation. Based on extensive literature in this field since the early 1990’s, the following is a description of the proposed sequence required for this skill acquisition. This process appears to consist of three distinct phases. In the first, learning/improvement in motor performance can be observed both behaviorally and neurologically from one training session to the next. In the intermediate phase, a consolidation period has been proposed. During this time the organism benefits from a period of non-practice, where improvement in motor performance has been observed hours to days after training has ceased, thus the skill continues to develop or consolidate even after practice. The third stage is a slow learning stage, where smaller gains are noticed across sessions. The authors add that with repeated practice the skill becomes both more automatic and resistant to interference.

Two different circuits have been proposed to be responsible for motor learning: a cortico-striato-thalamocortical loop and a cortico-cerebello-thalamo-cortical loop. It has been observed that the learning of sequential finger movements produces an activation or reorganization of the primary motor cortex which in turn produces changes in the cerebellum, striatum, and other motor cortical regions of the frontal lobe. With repeated practice and the development of automatic performance, the cerebellum has been observed to play a less active role, while on the other hand the striatum becomes more active (Ungerleider et al., 2002).

Motor cortex plasticity or activation can be induced through the repeated practice of motor sequences (Ungerleider et al., 2002). The practice of Tai Chi constitutes repeated practice of slow flowing and sequential movements. Ungerleider et al. (2002) suggest that the evolution of a specific representation requires long-term practice over several weeks, suggesting that a practice consisting of repeated motor sequences over several weeks, such as Tai Chi, may lead to cortical activation in practitioners.

Physiological and Psychological Benefits of Tai Chi

Research has established multiple physiological and psychological benefits of Tai Chi in populations of older adults. Some of these benefits tap into aspects of emotional, cognitive, behavioral and physiological well-being. Examples include: improved balance (Gatts, & Woollcott, 2005., Tsang, Hui-Chan, 2008., Xian Li, Qing Xu, & Hong, 2008., Lephart, Pincivero, Giraldo, & Fu, 1997., Gardner, Martin, & Jessell, 2000., Nguyen & Kruse, 2012), mood and heart rate (Jin, 1989), sleep quality, efficiency, duration, and a reduction in number of sleep disturbances (Li, et al, 2004., Irwin, Olmstead, & Motivala, 2008., Nguyen & Kruse, 2012), increased functional mobility, subjective psychological health, immune health (Yeh et al., 2006), stress and pain reduction (Abbott et al., 2007), and increased tactile acuity (Kerr et al., 2008). Physiological, emotional, and behavioral benefits of Tai Chi and isolated components of Tai Chi include: decreased anxiety and less hyperactivity in children with Attention Deficit Hyperactivity Disorder (ADHD) (Hernandez-Reif, Field, & Thimas, 2001), increased positive mood and decreased hyperactivity in children with severe learning disabilities and behavior problems (Baron & Faubert, 2005).

Although the benefits of Tai Chi have been demonstrated in physiological processes, behavior regulation, cognitive, and emotional functioning, these benefits have been observed in

samples of older adults and select populations of children, such as children with ADHD. Identifying positive effects of Tai Chi on other populations such as individuals with multiple disabilities is an area that requires more attention. In fact, no research has been conducted with a population of children whose phenotype consists of multisensory impairments, such as experienced by individuals with CHARGE syndrome. Before the effects of an adapted form of Tai Chi can be assessed on children with CHARGE, it is important to first adapt this practice to the unique sensory needs of these children.

Adaptations of Tai Chi for Individuals with Disabilities

Research on modifying and adapting Tai Chi is limited; however, Chen, Wang, and Liu (2006) proposed considerations to incorporate when modifying Tai Chi for older adults and individuals with physical disabilities. Their suggestions include: keeping the forms low impact and simple, and thus safe and easy to learn. The memorization of forms may be a challenge and may lead to frustration; however, if the forms are kept simple and easy to remember, the experience may be enjoyable (Li, Fisher, Harmer, & Shirai 2003., Chen et al, 2006). The authors also noted that while making the form shorter, and simpler, vital components of Tai Chi such as breathing, body posture, relaxation, and fluid movements are unchanged. The authors suggested that forms be presented in isolation and then linked and sessions should always commence with stretching and warm up, relaxation, and basic orientation to the body and form.

Li et al. (2004) examined a modified form of Tai Chi, incorporating the elements described above. This modified version was practiced by 48 balance-impaired older adults. Results of this study suggested that practitioners experienced significant improvements in self-reported health and well-being, mental and physical-performance, instrumental activities of daily living, physical performance measures of one-leg balance, walking speed, and time to rise from a chair. These

results suggested that adapted forms of Tai Chi that are low stress, simpler, and easier to follow may be just as effective and safe as other typical forms of Tai Chi.

Thus, Tai Chi has been successfully adapted to meet the needs of individuals with physical disabilities and balance-impaired adults. Lieberman, Haibach, and Schedlin (2012) provided suggestions when working on physical education practices with a child with CHARGE syndrome. First, they suggest that teaching the end goal may be more socially appropriate (e.g., throwing) than focusing on the foundational skill (e.g., grasp and releasing). Second, teaching open motor skills, which require active adaptation of motor skills (e.g., basketball, handball, and tennis) and not just closed motor skills, where the motor skills employed remain constant (e.g., bowling, archery, and running) is important to ensure that the curriculum they are exposed to is the same as their peers. Third, they also suggest that the child with CHARGE syndrome may require extended physical education classes to learn the physical activities. Thus, extending physical education classes 10 to 15 minutes might be a good idea, to ensure they make the same gains as their peers. Fourth, they add that it is imperative to ensure a trained support personnel provide 1:1 assistance to the child to ensure clarity and provide feedback and breaks when needed. They suggest that the area of adapting physical practices to meet the unique needs of children with CHARGE syndrome is an area that requires further research. It seems imperative that in adapting Tai Chi for children with CHARGE, any version should incorporate the teaching of open motor skills, teaching the goal skills in addition to foundational skills, and that someone, such as the parent or a trained professional be available to provide 1:1 instruction, clarity and feedback to the child when needed.

Barrey-Grassick (2011) reported on such a modified version of Tai Chi which she calls Fun Chi. Fun Chi, an adapted form of Tai Chi, takes into account the accommodations presented

by Chen et al. (2006) and Li et al. (2003). The forms are low stress, requiring less squatting, they are also interesting, simple and easy to follow. For example, instead of calling a move ‘Warm-up’ it is called the ‘Octopus Dance’ and instead of calling a form ‘Watering the Lotus Garden’ it is called ‘Watering Ann’s Garden’. Specific aspects that are incorporated include relaxation, diaphragmatic breathing and correct positioning of the forms.

Because children with CHARGE are not congregated in the same location, it is necessary to deliver the Fun Chi forms via a video to ensure all children receive the same instruction and to account for the fact that Fun Chi instructors cannot be provided for the families. It is possible that this video format of an adapted form of Tai Chi for children with CHARGE will require additional adaptations and modifications to meet the unique sensory needs of children with CHARGE syndrome. The purpose of this research project is to investigate the utility and social validity of a DVD format for the presentation of Fun Chi to children with CHARGE syndrome.

The Importance of Social Validity

Social validity is the social significance of the goals of the treatment, the social appropriateness of the treatment procedure; and the social importance of the effects of treatment (Wolf, 1978, p. 207). In assessing social validity participants provide valuable data regarding how the adapted practice meets their needs, values, and competencies. When adapting an intervention or practice it is important to take into account the participants’ opinion about the adapted practice. It is important to take into account participant perception because if an intervention is perceived to be socially acceptable there is greater probability that it will be implemented with fidelity than if the intervention is viewed as unacceptable (Lane & Beebe-Frankenberger, 2004). In ensuring a practice has been adapted in a socially valid manner, the practice or intervention as an independent measure gains validity and supports the goal that it

will be a valid measure when assessing its effects on a dependent measure. In adapting a movement based practice such as Tai Chi to children with CHARGE, it is particularly important to assess parent perception of the procedures to ensure that the video is sensitive to the multisensory needs of the child. Assessing these components will ensure that a more socially valid Fun Chi video can be developed to better meet the needs, values and competencies of these children and families.

Conclusion

Individuals with CHARGE syndrome may experience multiple anomalies that can interfere with their development and behavior. The ancient practice of Tai Chi has produced positive effects in aspects of physiological, behavioral, cognitive, and emotion functions. An adapted form of Tai Chi such as the one described by Barrey-Grassick (2011) may produce favorable physiological, emotional, and cognitive behavioral outcomes for individuals with CHARGE syndrome. However, it is of primary importance to first assess and establish the utility and social validity of an adapted form of Fun Chi so that the effects of Fun Chi can be properly and validly assessed in future studies.

CHAPTER III

METHOD

Participants and Setting

The participants in the current study were five families with a child with CHARGE syndrome, living in Michigan who responded to an invitation letter to participate sent by Deaf Blind Central: Michigan's Training and Resource Project (DB Central). DB Central sent the invitation letter to all families with a child with CHARGE syndrome in the state of Michigan, per their census. Participating families expressed interest in the study, agreed to carry out the entire six-week study in their home, and agreed to having the researcher observe their family practicing Fun Chi once in their home. All five children were males with CHARGE syndrome between the ages of 9 to 17, living in Michigan. Fun Chi was performed by the child with care givers, grandparents, siblings, or therapist. The five children participating in the study were mobile. Three used some spoken words, but primarily sign and pictures, one used gestures, sounds, and body movements, and the last communicated via noises interpreted by his parent and unlike the other four children, he had some degree of cognitive impairment. Table 1. through Table.5 show participant characteristics. This includes child characteristics (Table 1.), CHARGE syndrome characteristics/features (Table 2.), vision and hearing (Table 3.), and communication skills (Table 4.).

Table 1. *Child Characteristics*

	Child 1	Child 2	Child 3	Child 4	Child 5
Age	17	9	10	11	11
Age of onset of walking	3	NA	2.5	3	1.5
Total number of surgeries	8	15	28	8	5
Musculoskeletal problems	X	X	X	X	
Sleep problems	X	X	X		X

X=Present

Table 2. *CHARGE Syndrome Characteristic/Feature*

	Child 1	Child 2	Child 3	Child 4	Child 5
<i>Major CHARGE Characteristics</i>					
Coloboma of the eye	X		X	X	X
Choanal atresia or stenosis		X	X		X
Cranial nerve dysfunction/anomaly	X				X
CHARGE ear					
CHARGE outer ear	X	X	X	X	X
CHARGE inner ear	X		X	X	X
Vestibular problems	X		X	X	X
<i>Minor CHARGE Characteristics</i>					
Heart defects	X				X
TE (Tracheosophageal) fistula					
Kidney/renal abnormalities	X	X	X		
Growth deficiency	X	X	X		X
Typical CHARGE face	X		X	X	X
Palm crease (hockey-stick palmar crease)		X		X	
Obsessive-compulsive behavior/pervasive behavior	X	X	X	X	X

X=Present

Table 3. *Vision and Hearing*

	Child 1	Child 2	Child 3	Child 4	Child 5
Normal vision		L R		L	
Some trouble seeing				R	
Moderate difficulty seeing	L				L R
Much difficulty seeing			L R		
Totally Blind	R				
Normal hearing		L R			
Some trouble hearing				L R	
Moderate difficulty hearing	L				R
Much difficulty hearing	R		L R		L
Totally deaf					

L=Left, R=Right

Table 4. *Communication Skills*

	Child 1	Child 2	Child 3	Child 4	Child 5
Uses verbal or sign language in complete Sentences					
Uses some 2 or 5 word phrases and sentences using speech, signs, picture symbols, etc.	X		X	X	
Uses single words, signs, pictures, symbols, or objects to represent basic needs					
Uses behavior such as gestures, sounds, and body movements which most people can understand		X			X
Makes reactions or noise or behaviors which parent needs to interpret and that are difficult for an unfamiliar person to understand					X

X=Present

Instrumentation

Fun Chi Video

A DVD featuring a modified form of Tai Chi was developed specifically for this study. Fun Chi, the adapted form of Tai Chi was developed with the assistance Sharon Barrey in Perth, Australia. The DVD was designed so that children with CHARGE can perform the moves successfully. As mentioned by Barrey-Grassick (2011) Tai Chi has the least number of documented injuries of any sport, including Yoga and Pilates. Li et al. (2003) noted that Tai Chi is appropriate for elderly adults and disabled populations because all movements are relaxed, flowing, and balanced as the trunk lies erect at the center of all movement.

Fun Chi, takes into account the accommodations presented by Chen et al. (2006) and Li et al. (2003). The forms are low stress, requiring less squatting, they are also interesting, simple and easy to follow. For example, instead of calling a move ‘Warm-up’ it is called the ‘Octopus

Dance’ and instead of calling a form ‘Watering the Lotus Garden’ it is called ‘Watering Ann’s Garden’. The Fun Chi video lasted approximately 14 minutes and is divided into warm-up and Fun Chi exercises. Specific aspects that are modeled include relaxation, diaphragmatic breathing and correct positioning of the forms. Some of the considerations in developing this adapted form of Tai Chi video, include those proposed by Li, Fisher, Harmer, and Shirai (2003). The video was used by families for six weeks, three times per week for about 14 minutes per session.

Intent to Participate Form

Families interested in participating in the study completed the Intent to Participate Form (Appendix B). This form explained the parameters of the study and parents reported their willingness to carry out the study in their home, their openness to being observed once by the researcher, their ability to record all of their Fun Chi sessions with a flip camera provided by the researcher, and their ability to complete the project in its entirety.

Social Validity Questionnaire

The Social Validity Questionnaire (Appendix C) was completed by the parent at the end the second, fourth, and sixth week of exposure to the video. The social validity questionnaire rating form was used to rate their perception of the clarity and usefulness of the goals of the video, the procedures used in the video, and the effects of the video. This questionnaire was available on Survey Monkey™ for parents to complete.

Parent Treatment Integrity Checklist

The Parent Treatment Integrity Checklist (Appendix D) was available to parents as a reminder of aspects to monitor. Parents completed this on the days they used the Fun Chi video with their child. On the checklist parents checked the date and time of completion, if the video was complete in its entirety, if the practice was enjoyable, the degree of assistance the child required, and if the social validity questionnaire was completed.

Researcher Treatment Integrity Observation Checklist

The Researcher Treatment Integrity Observation Checklist (Appendix E) was completed by the researcher upon observing a family using the Fun Chi video. The researcher observed four of the five participant families. Items on the checklist included the following: was the video used as designed, did the child and parent appear to enjoy themselves, what level of assistance did the child appear to require, and did the parents complete the Parent Treatment Integrity Checklist after using the video. The researcher videotaped the observed Fun Chi session and shared the video with a research assistant who completed another Research Treatment Integrity Observation Checklist. Inter-rater reliability was computed comparing the observations of the primary researcher's observations with those of the research assistant by determining the total number of agreements divided by the number of agreements and disagreements on the Research Treatment Integrity Observation Checklist.

Procedure

A Fun Chi DVD was developed with the assistance of Sharon Barrey. Once the video was developed, Deaf Blind Central: Michigan's Training and Resource Project (DB Central) sent a letter of invitation for participation to all families in the state of Michigan with a child with

CHARGE syndrome between the ages of 7 to 17 who were part of their census. The letter (Appendix A) explained the study, its duration, Tai Chi, Fun Chi, and the requirements to participate. Interested families contacted DB Central and gave permission for their contact information to be shared with the primary researcher. These families completed the Intent to Participate Form on which they expressed their willingness to carry out the study in their home, their openness to being observed once by the researcher, and their ability to complete the project in its entirety. The families who had expressed their interest, were contacted via phone by the primary researcher. At this time correct addresses were confirmed, families were asked if they could record every Fun Chi session or just the first and last practice of Fun Chi, and a time and date to observe each family was set with each of the five families.

A packet containing the Fun Chi DVD, a flip camera, and a two gigabyte memory chip was sent to the four families who agreed to record the first and last session of Fun Chi and an eight gigabyte memory chip was sent to the one family who agreed to record every Fun Chi session. Additionally, a small video recorder, the Parent Treatment Integrity Checklist, a sample of the Survey Monkey™ version of the Social Validity Questionnaire, Parent Consent Form, Child Assent Form, CHARGE syndrome Demographic Form, and two return envelopes were mailed to each of the five families. Participating families were called and informed regarding the day to expect the packet. Families were also called on the day their package was expected to arrive to ensure that it had arrived.

Throughout the six-week Fun Chi practice, parents and their children used the video three times per week for a period of about 14 minutes per session. One family recorded all of their Fun Chi sessions, while the other four recorded only the first and last Fun Chi session. Upon completion of each session, parents completed the Parent Treatment Integrity Checklist. At the

end of week two, four, and six, parents completed the Social Validity Questionnaire on Survey Monkey™. A day before the end of week two, four, and six, parents received an e-mail reminding them to complete the questionnaire online. A qualitative analysis of parent feedback regarding their satisfaction with the procedures, goals, and suggestions for improvement was conducted.

CHAPTER IV

RESULTS

Research Findings

Child One

Child one was 17-years-old, started walking at age three, experienced eight surgeries, had musculoskeletal problems and sleep problems. He had moderate difficulty seeing in his left eye and total blindness in his right eye. He displayed five out of six major CHARGE syndrome features and six of nine minor CHARGE syndrome characteristics (refer to Table 1). Regarding his vision, he had moderate difficulty hearing in his left ear and much difficulty hearing in his right ear. He used some two-or five-word-phrases and sentences using speech, signs, and picture symbols. He displayed the ability to imitate and complete Fun Chi forms with the assistance of a live model.

The first research question was whether the video helped parents do Fun Chi with their child. Child one's parent reported at the end of weeks four and six that the video did not help them perform Fun Chi with their child. The parent also consistently reported that her son required considerable assistance in performing the forms. Based on researcher observation, child one appeared to imitate more fluently when observing a live model instead of the television screen.

The second question was whether parents found the video easy and clear to use. Child one's parent perceived the video to be easy and clear to use only at the end of the second week. She thought there was too little contrast between the instructor and the background and that the use of closed caption, signing, and slower instructions would be beneficial for her child.

The third question was whether the parents found the goals of the video acceptable and clear. The goals of the video were deep breathing, correct posture, ability to follow Fun Chi steps and having fun. Child one's mother found the goals of the video clear and acceptable until the end of week four, by the end of week six she did not think the goals were clear or acceptable.

The fourth question was whether the procedures demonstrated in the video were clear and acceptable. The procedures in the video include the organization of the video, the clarity of instructions, the length of the video, the appropriateness and clarity of language, appropriateness of the names given to the forms, a fun presentation of the forms, visual contrast between the Fun Chi instructor and the background, and the clarity of explanation given to the importance of breathing and relaxation. At the end of week two, child one's parent found that forms were not presented in an enjoyable manner and that the video was too long for her child. The mother reported that her child may benefit from the image being larger, possibly alluding to the fact that the image did not cover the entire screen, but instead only the vertical portion of the screen. Her child used his caretaker as a live model in order to complete the forms. It is possible that the child had difficulty seeing and thus imitating the instructor on the screen.

By the end of week four and week six the parent found that the following procedures were not appropriate: the language used in the video (i.e., the instructor explained forms too quickly), the names of the forms were not easy to understand, there was not enough visual contrast between the instructor and the background, and poor clarity of explanation given to the breathing and relaxation. The parent suggested that instructions be broken into smaller chunks, that instructions be provided in sign language and closed caption, and that brighter colors be used to increase the contrast between the instructor and the background.

The fifth question was whether the observable effects of the repeated practice of the video were positive. Child one's parent reports to have enjoyed practicing Fun Chi from week one until the end of week six. She indicated that her son enjoyed Fun Chi and was relaxed during and after its practice from the end of the initial week until the end of week four. From the initial practice of Fun Chi until the last, the parent reported that he appeared confused and required extensive assistance in performing the forms. His parent noticed no improvements in sleep, in his ability to deal with his emotions, or ability to respond to difficult situations. Although no changes in balance were perceived at the end of week two or six, at the end of week four his parent perceived an improvement in his balance. In summarizing the experience she had with her child, the parent reported that her son often became "aggressive and avoided doing Fun Chi", but she enjoyed seeing how some small progress was made in his forms. She adds that Fun Chi might be an "enjoyable option for just the parent."

Child Two

Child two was 9 years-old, had experienced 15 surgeries and displayed musculoskeletal problems and sleep problems. He exhibited two of six major CHARGE characteristics and five of nine minor CHARGE characteristics. He had normal vision and normal hearing. To communicate he used behaviors such as gestures, sounds, and body movements which most people can understand. He displayed difficulty independently imitating Fun Chi forms.

Regarding the first question as to whether the video helped parents do Fun Chi with their child. Child two's parent reported at the end of weeks two, four, and six that the video helped them perform Fun Chi with their child. The parent also consistently reported that their child required considerable assistance in performing the forms, often in the form of hand-over-hand assistance and directly positioning the child.

The second question was whether parents found the video easy and clear to use. During the duration of the study child two's parent found the video easy and clear to use.

The third question was whether the parents found the goals of the video acceptable and clear. Child two's mother consistently perceived the goals of the video to be clear and acceptable during the entire duration of the study.

The fourth question was whether the procedures demonstrated in the video were clear and acceptable. The procedures the parent found acceptable at the end of weeks two, four and six were the organization and sequencing of the video, the language used, the clear and easy instructions, the enjoyable names for the forms, the enjoyable presentation of the forms, the length of the video, and the clear explanation of relaxation and breathing in the video. However, she perceived that there was not enough visual contrast between the instructor and the background. Her child was often very close to the television screen, possibly due to difficulty in seeing. The parent also perceived a visual distraction (i.e. cat) present in the video, side comments from the instructor were distracting for her child, and the "punch the polar bear" form was too long for her child.

The fifth question was whether the observable effects of the repeated practice of the video were positive. Child two's mother reported to enjoy practicing Fun Chi throughout the entire study. Although her child appeared confused from week one until the end of week six and required extensive assistance in performing the forms during this time, he appeared relaxed during and after the practice of Fun Chi through the end of week four and appeared to enjoy it through the end of week two and from the end of week four until the end of week six. This inconsistency in enjoyability is consistent with her report of her child's fluctuating positive response towards the video. No improvements in his sleep, balance, or ability to deal with

frustration and respond to difficult situations were noticed. In summarizing the experience that she and her child had with Fun Chi, she noted that she enjoyed reminding him to focus on balance and flexibility during the Fun Chi sessions, and that her son “was often resistant but at times enjoyed it.”

Child Three

Child three was 10-years-old, walked at the age of two and a half, had experienced 28 surgeries, and displayed musculoskeletal and sleep problems. He exhibited five of six major CHARGE characteristics and five of nine minor CHARGE characteristics. He displayed considerable difficulty seeing from both his left and right eyes and considerable difficulty hearing from both his left and right ears. He used some two or five word phrases and sentences using speech, signs, and picture symbols. He displayed a good imitation skills.

The first question was whether the video helped parents do Fun Chi with their child. Child three’s parent reported at the end of weeks two, four, and six that the video helped them perform Fun Chi with their child. From the first week the child performed all the forms independently, but the parent reported that he required less and less assistance (i.e., verbal prompts and gentle touch) in performing the forms. Assistance for this child consisted or repetition of instructions and cuing in the form of a gentle touch.

The second question was whether parents find the video easy and clear to use. From the end of week two until the end of week six the parent of child three found the video easy and clear to use.

The third question was whether the parents find the goals of the video acceptable and clear. From the end of week two until the end of week six, child three’s mother found the goals of the video to be clear and acceptable.

The fourth question was whether the procedures demonstrated in the video were clear and acceptable. At the end of weeks two, four, and six, child three's mother perceived the language used in the video to be understandable, instructions to be clear and easy to follow, the importance of breathing and relaxation clearly explained, the names used for the forms easy to understand, the forms presented in a fun and enjoyable manner, enough visual contrast between the instructor and the background, no visual or auditory distractions, the organization and sequencing of the video easy to follow, and the length of the video appropriate for her child. The parent suggested the addition of several workout sessions in the video.

The fifth question was whether the observable effects of the repeated practice of the video were positive. Child three's parent reports that both she and her child enjoyed using the Fun Chi video throughout the entire study. Throughout the duration of the study the parent consistently perceived that the child experienced no confusion, appeared relaxed during and after Fun Chi, and performed the forms independently with some assistance from her. The parent perceived the child to experience a decrease in sleep issues by the end of the second week. This was not observed by the end of week four or week six. The parent also noticed a decrease in balance issues both at the end of week two and the end of week six. Lastly, she perceived that the child's ability to deal with frustration and respond to difficult situations had improved by the end of week six.

Child three's parent summarizes the experience she had with her child, "We enjoyed our quality time doing Fun-Chi and it has improved behavior in both of us. At times we would stop and drop everything and tell one another 'Let's do our Fun Chi!' My son has seen me frustrated and told me to stop and do Fun Chi. I have seen that this has changed us both tremendously." Additionally, she enjoyed seeing her child's progress from week to week and reports that her

child would remind her about doing Fun Chi and would do Fun Chi in public places to greet people.

Child Four

Child four was 11-years-old, walked at the age of three and had experienced eight surgeries and experienced musculoskeletal problems. He displayed four of six major CHARGE characteristics and four of nine minor CHARGE characteristics. He had normal vision in his left eye, some trouble seeing in his right eye, and some trouble hearing in both his left and right ears. He used some two or five word phrases and sentences using speech, signs, and picture symbols. He displayed good imitation skills.

The first question was whether the video helped parents do Fun Chi with their child. Child four's parent reported at the end of weeks two, four, and six the video helped her perform Fun Chi with her child.

The second question was whether parents found the video easy and clear to use. During the duration of the study the parent found the video easy and clear to use.

The third question was whether the parents found the goals of the video acceptable and clear. Consistently from week to week child four's parent perceived the goals of the video to be clear and acceptable.

The fourth question was whether the procedures demonstrated in the video were clear and acceptable. From the beginning of the study, until the end of the study, child four's mother perceived the language used in the video to be understandable, instructions to be clear and easy to follow, the importance of breathing and relaxation clearly explained, the names used for the forms easy to understand, the forms presented in a fun and enjoyable manner, no visual or auditory distractions, the organization and sequencing of the video easy to follow and the length

of the video appropriate for her child. The parent perceived that there was not enough visual discrimination between the instructor and the background and suggested that the instructor wear brighter colors. The mother also commented that although the length of the video was appropriate, the warm-up section is a bit too long. She also suggested that several workouts be included in the video, instead of just one.

The fifth question was whether the observable effects of the repeated practice of the video were positive. Throughout the entire study, the parent reported that both she and her child enjoyed practicing Fun Chi, that her child appeared relaxed during and after Fun Chi, that her child experienced no confusion and was able to perform the Fun Chi forms primarily independently with some assistance. The parent noticed no changes in sleep or in the child's ability to deal with frustration and respond to difficult situations. However, by the end of week six she perceived a decrease in balance issues. Child four's parent summarizes the experience she and her child had with Fun Chi by commenting, "we have learned to think about Fun Chi in times of anxiety and do our Fun Chi instantly. It calms us both and brings us back to calmly re-group. Our experience has been definitely life changing."

Child Five

Child five was 11-years-old, walked at the age of one and of half and had undergone five surgeries. He experienced sleep problems. He displayed all major CHARGE characteristics and four of nine minor CHARGE characteristics. He displayed moderate difficulty seeing from both his left and right eyes and some trouble hearing from both his left and right ears. To communicate he used behaviors such as gestures, sounds, and body movements which most people can understand and made reactions or noises or used behaviors his parent needed to

interpret and that are difficult for an unfamiliar person to understand. He displayed difficulty independently imitating Fun Chi forms.

The first question was whether the video helped parents do Fun Chi with their child. The parents reported that at no point during the study did the video help her perform Fun Chi with their child. They also consistently reported that their child required considerable assistance in performing the forms. This assistance consisted of hand-over-hand and direct positioning of his body.

The second question was whether parents found the video easy and clear to use. The parent found the video easy and clear to use during the duration of the study.

The third question was whether the parents found the goals of the video acceptable and clear. From the beginning of the study until the end of the study the parent of child five found the goals of the video to be clear and acceptable.

The fourth question was whether the procedures demonstrated in the video were clear and acceptable. At the end of weeks two, four and six the parent found the organization and sequencing of the video organized, the instructions clear and easy to follow, names for the forms were easy to understand, and the importance of relaxation and breathing clearly explained in the video. However, she perceived that there was not enough visual contrast between the instructor and the background, the video was too long for her child, the forms were not presented in an enjoyable manner and the language used was not understandable for her child.

The fifth question was whether the observable effects of the repeated practice of the video were positive. The parent reported that the child consistently appeared confused and required extensive assistance to perform the forms. The parent reported that Fun Chi was not enjoyable for herself or the child. However from week to week the child consistently appeared

relaxed during and after Fun Chi. No improvements were perceived in the areas of sleep, balance, or ability to deal with frustration and ability to respond to difficult situations. In summarizing the experience that she had with her child, the parent commented that she wished the video was more appropriate in meeting the needs of children with CHARGE who have cognitive impairments.

Tables 5, 6, and 7 provide a general depiction of parent perception to research questions one through five.

Table 5. *Parents Who Perceived the Goals of the Video Clear and Acceptable*

	End of Week 2	End of Week 4	End of Week 6
Video helps parents do Fun Chi with their child	1,2,3,4	2,3,4	2,3,4
The video is clear and easy to use	All	2,3,4,5	2,3,4,5
The goals of the video are clear and acceptable	All	All	2,3,4,5

1 = Child one's parent, 2 = Child two's parent, 3 = Child three's parent, 4 = Child four's parent, 5 = Child five's parent

Table 6. *Parents Who Perceived Procedures in the Video Clear and Acceptable*

	End of Week 2	End of Week 4	End of Week 6
Organization and sequencing of the video was appropriate	All	2,3,4,5	2,3,4,5
Length of the video was appropriate	All	1,2,3,4	2,3,4
Language used in the video was understandable	All	2,3,4,5	2,3,4,5
Names used for the forms were fun and easy to understand	All	All	All
Forms were presented in a fun manner	2,3,4	1,2,3,4	2,3,4
Appropriate contrast between the Fun Chi instructor and background	1,3	3,4	3,4
The importance of breathing is clearly explained	All	2,3,4,5	2,3,4,5
The importance of relaxation is clearly explained	All	All	2,3,4,5

1 = Child one's parent, 2 = Child two's parent, 3 = Child three's parent, 4 = Child four's parent, 5 = Child five's parent

Table 7. *Parents Who Perceived Positive Outcomes of the Fun Chi Video*

	End of Week 2	End of Week 4	End of Week 6
Parent reported to enjoy Fun Chi	1,2,3,4	1,2,3,4	1,2,3,4
Parent reported to be pleased with the effects of Fun Chi	1,2,3,4	2,3,4	2,3,4
Child did not appear confused during the practice of Fun Chi	3,4	3,4	3,4
Child performed forms individually	3,4	3,4	3,4
Child performed forms with some assistance	1,2,3,4	2,3,4	1,2,3,4
Child performed forms with extensive assistance	1,2,5	1,2,5	1,5
Child appeared relaxed during Fun Chi	1,2,3,4	1,2,3,4	2,3,4
Child appeared relaxed immediately after Fun Chi	1,2,3,4	1,2,3,4	2,3,4
Child is having less sleep issues	3	None	None
Child's balance has improved	3	1	3,4
Child is dealing better with frustration	3	3	3
Since starting to practice Fun Chi, child is responding more appropriately to situations and events that would previously have been difficult for him to cope with	3	3	3

1 = Child one's parent, 2 = Child two's parent, 3 = Child three's parent, 4 = Child four's parent, 5 = Child five's parent

Qualitative Visual Analysis of the Child's Fun Chi Performance

A qualitative visual analysis of four of the five children was conducted by the researcher based on videos recorded of the first practice of Fun Chi and the last practice of Fun Chi for child one, child three, and child five. All but one session of Fun Chi was analyzed for child four. Three specific qualitative aspects that were explored were enjoyability, independence, and improvement in form completion.

Child One

Based on the first and last video of the recorded practice of Fun Chi for child one, it appears that the degree of assistance required significantly decreased. During the first practice he required assistance from both his mother and his caregiver in completing the Fun Chi forms. In his last practice of Fun Chi he required hand-over-hand assistance, signing, cues (i.e., pointing) and modeling from his caregiver. It should be noted that he appeared to look more at the caregiver and imitate the caregiver than he did the Fun Chi instructor on the screen.

During the last session he successfully imitated without assistance the forms requiring him to swing his arms from side to side, up and down, lifting his arms upward above his head, and alternately lifting a knee to chest. During the first session he was able to only partly lift his arms upward above his head and he could lift his knees to chest only while grabbing onto his caregiver with both hands. The child's attentiveness also significantly increased from the first video to the last video. It was also noticed that during his first practice of Fun Chi he walked away, but during his last session he completed the session in its entirety and appeared to enjoy himself. Based on parent report, the child appeared to enjoy Fun Chi during the first two weeks and the last two weeks, but not as much in-between.

Child Two

Although child two's mother attempted to record the first and last session of Fun Chi, the memory drive that was returned contained no recorded video. His mother reports that her child had difficulty independently imitating any forms, required extensive assistance (i.e. hand-over-hand and signing) and did not enjoy any of his Fun Chi sessions.

Child Three

During the first session of Fun Chi child three required repetitions of instructions and cuing in the form of a gentle touch to guide his attention to the leg(s) he needed to move. During this session he referred to both the instruction from the video instructor and his mother for directions. He appeared to complete most forms without much assistance. During the last session, he appeared to require less verbal prompting from his mother while completing the forms. During both the first and last session his mother provided the verbal prompt of "slower." He also appeared to require prompts when doing movements that required his legs. The degree of attentiveness appeared the same in both the first and last sessions. Based on parent perception, he enjoyed all Fun Chi sessions. He appeared to enjoy himself during both the first and last recorded sessions.

Child Four

Child four's mother agreed to record every Fun Chi session. This consisted of three sessions every week for six weeks. All but one session were successfully recorded. The session that was not recorded, appeared as a picture and not a video, thus it was not available for visual analysis. Based on visual analysis of seventeen videos, it appears that initially his mother provided some hand-over-hand assistance, modeling and verbal prompts. Although from week

one he completed most forms entirely by himself, by week three there appeared to be an increase in the range of movement he could achieve with his arms. By week three he also began to do Fun Chi almost entirely on his own. By this time, with some forms, he exhibited a greater ability to lift his arms higher and move them away from his chest. It is possible that he could have benefited from continued parent hand-over-hand and prompts when completing the energy ball form, a form on which he made little improvement. Additionally, from week-to-week it also appeared that he lost his balance less frequently. Based on parent report, he enjoyed all Fun Chi sessions. This is also apparent in all the recorded sessions.

Child Five

During the first session child five required extensive assistance in completing the Fun Chi forms. His caregiver was positioned on her knees directly behind him and used arm-over-arm, positioning of his legs, and signing. During the first session, the child refused to participate five times. Redirection and visual timers were used to guide him back to Fun Chi. At times after being redirected he appeared to enjoy himself, evidenced by his smiling and giggling. Other times he seemed unhappy, evidenced by his grumbling and sad facial expression.

During the last Fun Chi session the child refused to participate three times. Although arm-over-arm, positioning of his legs, and signing continued to be used, he nevertheless did perform two forms completely independently during the last session: he moved his ankles in circles and lifted his knees to his chest. During both the first and last sessions it was noticed that the child positioned himself very close to the television screen, leaving about 1 to 2 feet between himself and the screen, and at other times was even closer. It is possible that the image was too small for him to see. Based on parent report, he appeared to enjoy sessions through the end of week two.

Inter-rater Agreement

The researcher conducted one observation in four of the five homes. Although the researcher set up home visits and observations via Skype® with the fifth family, family circumstances prevented home visit with child five. Each of the four available families was observed and the Researcher Treatment Integrity Observation Checklist was completed by the researcher. The four sessions were also recorded and watched by a research assistant to determine inter-rater agreement of the observations conducted in the home. The inter-rater reliability was determined using item-by-item comparisons. The inter-rater reliability was found by determining the total number of agreements divided by the number of agreements and disagreements on the completed Research Treatment Integrity Observation Checklists. The inter-rater agreement was found to be 88%

CHAPTER V

DISCUSSION

There is limited literature on interventions and adapted interventions that meet the specific and multiple needs of children with CHARGE syndrome. This study demonstrates that Fun Chi, as an adapted movement-based practice, is functional and enjoyable for some children with CHARGE syndrome and their families; however, some sensory adaptations still require refinement to ensure the Fun Chi video be functional and enjoyable for most children with CHARGE syndrome. This study shed light on specific areas that parents of children with CHARGE syndrome consider important when utilizing Fun Chi, which may be helpful when adapting other interventions as well. The results of this study also will facilitate the development of a video that will be more socially valid and tailored to specific needs of children with CHARGE. In ensuring that the Fun Chi video is socially valid, it is possible that in future studies, parents will be likely to implement Fun Chi with fidelity and thus yield valid results for assessing the effects of Fun Chi.

There was some variability in response regarding the first research question, whether the video helped parents do Fun Chi with their child. The two children who had difficulty both were reported as having cranial nerve anomalies and heart defects. They were also very visually impaired with considerable deafness. It is possible that parents found their child to require so much assistance to perform the forms, that the video alone was not the ideal way for them to engage in Fun Chi. These two parents probably felt they were doing Fun Chi to their child instead of with their child. Although some parents and children had minimal issues with the video, their comments shed light on the importance of creating a video that accommodates not just the physical needs of the child with CHARGE, but most importantly the sensory needs.

Child one often imitated his caregiver or parent and received some hand-over-hand assistance and signed instructions from parent or caregiver in order to perform the forms, thus the video alone was not enough to do Fun Chi. It is interesting to note that his mother reported that Fun Chi would be an enjoyable activity for the parent alone. Child five and child two required hand-over-hand and manual positioning during the duration of the study, their difficulty imitating any form and needing continual parent assistance, support the idea that the video alone was not enough for the parent and child to perform Fun Chi. Although child three and child four also required some assistance in the form of verbal prompts and hand-over-hand assistance, it is possible that this amount of assistance complemented the video and did not distract, hinder, or become burdensome to the parent, as may have been the case for parent one and parent five. Although the video was functional for some families, creating a video that better meets the visual needs of most children may ensure that the parent does not have to work so hard in assisting the child in understanding and following along with the video.

Findings for the second and third research questions suggest that most parents found the video easy and clear to use and felt the goals of the video were clear and acceptable. However, the parent who provided extensive assistance while attempting to facilitate her child's independence, may have perceived the video to be unclear, not easy to use, and the goals unclear and not acceptable. This may have been the case for child one, who required extensive assistance during the duration of the study and at times became aggressive and avoided Fun Chi. This may have contributed in part to the mother's change in perception about the clarity and acceptability of goals of the video. His mother perceived he would benefit from greater contrast in the video, closed captioning, signing, and slower instructions. It is possible that the absence of this information hindered the clarity and acceptability of the goals of the video. For example, a

signed explanation of the deep breathing and correct posture may have been more functional and appropriate for her child. Additionally, the same parent, unlike all other parents who found the video clear and easy to use at every phase, only found the video clear and easy to use through the end of week two. Perhaps the degree of assistance that she had to provide became frustrating to her, thus the Fun Chi video's clarity and ease of usability was perceived as poor. It is interesting that although parent two and parent five also provided extensive assistance to their child, they did not report finding the video unclear and difficult to use. This may be attributed to the fact that they provided their children with extensive direct positioning of limbs; thus to them the video was clear and easy to use because the child only had to allow themselves to be led. Child one often imitated the parent or caregiver as a live model, and so the parent/caregiver had to provide more assistance, either as a model, by signing instructions, or providing hand-over-hand, and so to parent one the video was overall not functional for her child.

Based on the fourth research question which addressed the clarity and acceptability of procedures, it appears that some modifications are necessary to ensure the Fun Chi video meets the sensory needs of children with CHARGE. Parent feedback, researcher observation, and visual analysis of the Fun Chi sessions provide valuable direction regarding specific components that should be included in the next version of the Fun Chi video to ensure it is both functional and enjoyable for most children with CHARGE. It is possible that unrefined visual aspects of the video hindered their ability to imitate the forms and enjoy Fun Chi. Some children were observed and reported to either imitate their caregiver or position themselves very close to the television screen. Based on parent feedback, the video to be produced for future research needs to incorporate the following characteristics. Regarding visual changes, visual contrast between the instructor and the background needs to be increased, sign may be added, and the video should

take up the entire screen and not just a vertical portion of the screen. It may also be helpful to avoid visual distractions, such as the cat that approaches the instructor in the current video.

Regarding auditory changes, it will be important to keep the language as simple as possible and shorten the length of the warm up and punch the polar bear forms. Adjusting the Fun Chi video to meet the sensory needs of children with CHARGE may make the video more functional and thus more enjoyable for most children with CHARGE syndrome.

In determining how to best adapt this practice to children with CHARGE syndrome it is important to not just note specific procedures of the video that need to be further adapted, but characteristics of the children who had great difficulty with Fun Chi and those who did not. First, it is interesting to note that per visual analysis of recorded Fun Chi sessions, even the children who required the most extensive assistance in performing the forms demonstrated an increased ability to perform at least a couple of the forms by the end of week six. Regarding specific characteristics of children who struggled with Fun Chi, it is possible that cognitive impairment in the case of child five impacted his imitative ability. However, in the case of child one and child two it is possible that imitative ability was hindered by lack of visual contrast and other properties of the video. This may indicate that imitative ability and tied to that, the ability to visually decipher the video are related to the ability to fully engage in the video, enjoy the video, and possibly benefit from it. For child three and four physical stability was not an issue, for child one, two and five who required extensive assistance, it is unclear whether physical stability was an issue. Issues reported by parents these were those tied to the visual, auditory and imitative aspects.

Regarding the observable effects of the repeated practice of the video, it is apparent that those children who displayed a better ability to imitate the Fun Chi forms either independently or

with some assistance appeared to both enjoy Fun Chi consistently and according to parent report, at one or more phases displayed improved balance and or sleep and a better ability to deal with emotions. These parents reported that their child appeared relaxed during and after Fun Chi. On the other hand, those children who required the most assistance at one or more phases, either in the form of direct positioning, hand-over-hand assistance, or the use of a live model and sign, appeared not to enjoy Fun Chi and per parent perception, did not appear relaxed during and after Fun Chi, and experienced no improvements in changes in sleep, balance, or ability to deal with emotions. Thus, the child's ability to actively engage in Fun Chi may be associated with positive outcomes; however, this remains to be tested. Creating a video that takes into account parent suggestions regarding visual and auditory modifications when developing a more tailored Fun Chi, will provide the avenue to more accurately assess the true effects of this parent friendly, tailored and modified practice on children with CHARGE syndrome.

Limitations

Although the sample consisted of children who had various degrees of CHARGE characteristics (early exposure to hospital stays and surgeries, problems with communication, degrees of vision and hearing loss, and difficulty with imitation) a sample size of five is considered small so the results cannot be generalized to a general population of children with CHARGE syndrome. In addition, the sample consisted of only males. Also, out of the five families in the study only four were available for observations and the same family who was not available for an observation did not correctly record sessions with the provided video recorder. Lastly, although much effort went into creating a Fun Chi video, the quality of the video was limited due to financial constraints and time availability. However, the goal was not to have a perfect video at this stage of the research, but rather to determine whether intervention using Fun

Chi could be administered in this format and determine what specific aspects needed to be tailored to meet the needs of children with CHARGE.

Future Studies

The present study demonstrates that Fun Chi is an intervention that can be successfully administered through a video format to some children with CHARGE. In addition, the utilization of parent feedback and researcher observation should enable researchers to create a more superior Fun Chi video that many children with CHARGE will be able to access and enjoy. Once created, that video can be used to investigate the ability of Fun Chi to improve aspects of the lives of children with CHARGE. For example, sleep is an area that individuals with CHARGE often struggle with (Hartshorne et al., 2009) and this is an area where Tai Chi has been found to produce positive effects (Li, et al, 2004., Irwin et al., 2008., Nguyen & Kruse, 2012). It is also possible that Fun Chi could positively impact balance, another area children with which CHARGE syndrome struggle and which Tai Chi has demonstrated to positively influence (Gatts, & Woolcott, 2005., Tsang & Hui-Chan, 2008., Xian Li, Qing Xu, & Hong, 2008., Lephart, Pincivero, Giraldo, & Fu, 1997., Gardner, Martin, & Jessell, 2000., Nguyen & Kruse, 2012). A third area that an adapted of Tai Chi may potentially impact in children with CHARGE is self-regulation. Self-regulation can be understood as the goal directed and adaptive management of internal and external stimuli. Tai Chi has been found to have positive behavioral effects on children with ADHD (Hernandez-Reif, Field, & Thimas, 2001) and children with learning disabilities and behavioral problem (Baron and Faubert, 2005). The effects of an adapted form of Tai Chi in children with CHARGE remains to be tested, but this first study laid the necessary groundwork for adapting this practice to meet the challenges of children with CHARGE syndrome.

APPENDICES

APPENDIX A

INVITATION LETTER

Dear Parent/Caregiver,

My name is Maria Ramirez and I am currently a fourth-year school psychology doctoral student at Central Michigan University. To fulfill the requirements for my doctoral degree, I will be conducting a series of studies under the supervision of Dr. Tim Hartshorne. The goal of this first study is to determine the usefulness of a DVD based on an adapted form of Tai Chi (Fun Chi) developed for with children with CHARGE syndrome.

An invitation to participate in this study has been extended to you because you have been identified by DeafBlind Central as having a child diagnosed with CHARGE syndrome.

Please read the information provided in the Intent to Participate Form to help you make an informed decision about your family's participation in this study. Your family's participation or non-participation will not affect services that you or your child may receive through DeafBlind Central. If you have any questions, please call Maria Ramirez (815) 298-4987 or Dr. Hartshorne 989-774-6479.

Thank you for your time and consideration,

Maria Alejandra Ramirez

APPENDIX B

INTENT TO PARTICIPATE FORM

Study Title:

Validation of a Tai Chi video to improve self-regulation, balance, and sleep in children with CHARGE syndrome.

Research Investigators' Names and Departments:

Maria A Ramirez – Graduate Researcher

email: ramir1ma@cmich.edu **phone:** 815-298-4987

Timothy Hartshorne – School Psychology Professor at Central Michigan University

email: harts1ts@cmich.edu **phone:** 989-774-6479

Introductory Statement

This study is designed to establish the usefulness of a video of an adapted form of Tai Chi (Fun Chi) for children with CHARGE syndrome. If you have questions about the study please feel free to contact either investigator via email or phone.

What is the purpose of this study?

The purpose of this study is to get parent feedback and determine the clarity and usefulness of a Fun Chi DVD. Parent feedback will guide the development of an improved video which will be utilized in a second study to evaluate the effects of Fun Chi on self-regulation, balance, and sleep on children with CHARGE syndrome.

What will my child and I do in this study?

You and your son or daughter will watch the Fun Chi video and follow along for about 15 minutes three times per week for a period of six weeks. In addition, you will complete the parent opinion questionnaire at the end the second, fourth, and sixth week of use of the video, and the treatment integrity checklist on the days Fun Chi is practiced. With the Flip camera that will be provided, you will record your families' very first and last practice of Fun Chi. Two volunteering families will record all the sessions of Fun Chi.. Lastly, on a date agreed by you and the researcher, the researcher will observe you and your child practicing the Fun Chi video in your home.

How long will it take my child and I to do this?

The duration of the study will be six weeks. During this time you will watch the video three times per week for about 15 minutes per session. You will decide the specific days of the week and time of day Fun Chi will be practiced. At the end of the study you can keep the Fun Chi DVD.

Are there any risks of participating in the study?

No, Fun Chi is a low stress adapted form of Tai Chi that was designed by a Tai Chi instructor and deafblind specialist knowledgeable in the somatosensory and behavioral characteristics of children with CHARGE syndrome.

What are the benefits of participating in the study?

At the moment there is limited research on interventions that improve the social and behavioral functioning of children with CHARGE syndrome. This study will provide a first step towards developing a family friendly and enjoyable intervention to be used in the home with children with CHARGE syndrome.

Will anyone know what my child or I say or do in this study (confidentiality)?

Information regarding you and your child will only be viewed by the researcher and research assistant. Each family will have a number associated with their data and identifying information will be kept separately from the coding system. I will be the only one able to match the data to the identity of the family. Recording of Fun Chi provided by parents to the researcher will be kept in a computer in the CHARGE lab and will be destroyed after the completion of study. The videos of families who withdraw from the study before its completion will be immediately destroyed. In the case this study is published in a journal article, no names of children or families will appear in the paper.

Will I receive any compensation for participation?

Families participating and completing this study will keep the Fun Chi video and a Kodak video camera and either an 8GM memory card or a 32GB memory card.

Is there a different way for us to receive this compensation or the benefits of this study?

There is no other way of attaining a video.

Who can I contact for information about this study?

Maria A Ramirez – Graduate Researcher

email: ramir1ma@cmich.edu **phone:** 815-298-4987

Timothy Hartshorne – School Psychology Professor at Central Michigan University

email: harts1ts@cmich.edu **phone:** 989-774-6479

Please place a checkmark (X) next to the following statements you agree to:

- I am willing to carry out the study in my home
- I believe that my family and I can complete this study in its entirety
- I am willing to record my family practicing Fun Chi on the first and last day of the study
- I am willing to record ALL (3 times per week for 6 weeks) of the session of Fun Chi we carry out in the home
- I am willing to schedule a date in which the researcher can observe my family practicing Fun Chi

You are free to withdraw your consent and intent to participate, and discontinue the participation of yourself and your child in the project at any time without penalty.

If you are not satisfied with the manner in which this study is being conducted, you may report (anonymously if you so choose) any complaints to the Institutional Review Board by calling 989-774-6777, or addressing a letter to the Institutional Review Board, 251 Foust Hall Central Michigan University, Mt. Pleasant, MI 48859.

My signature below indicates that all my questions have been answered. I intent to participate in the study and agree to participate in the project as described in the two pages I read describing the study.

Signature of Parent/Guardian

Date Signed

Name of Child



After signing, please put this form in the post marked envelop and mail

appropriate. If not, circle: too dark OR too light
The colors of the Fun Chi instructor were appropriate. If not, circle: too dark OR too light
There was enough visual contrast between the background and instructors clothes
There were no visual distractions for my child in the video
There were no auditory distractions for my child in the video
The sequencing/organization of the video was easy to follow
The video is too long for my child
The video is too short for my child
The length of the video is appropriate for my child
I am very pleased with the video, there is nothing I would change

Directions: Rate your acceptability of the following statements.



	Strongly Agree	Agree	Strongly Disagree
Effects of the video: Are you satisfied with the effects?			
My child consistently appeared to enjoy (laughed, smiled, etc.) doing Fun Chi			
I/my partner and I consistently enjoyed doing Fun Chi			
My child did NOT appear confused (looked around, asked for assistance) with directions and forms			
For the most part, my child performed the forms individually thorough the video			
During the Fun Chi video my child appeared relaxed			
Immediately after the video my child appeared relaxed			
Overall, we have all been pleased with the effects of Fun Chi			
Since starting to practice Fun Chi, I have observed that my child is having fewer difficulties with sleep			
Since starting to practice Fun Chi, I have observed that my child's balance has improved			
Since starting to practice Fun Chi, I have observed that my child is better at handling frustration and controlling his/her emotions			
Since starting to practice Fun Chi, I have observed that my child is responding more appropriately to situations and events that would previously have been difficult for him/her to cope with			

APPENDIX D

PARENT TREATMENT INTEGRITY CHECKLIST

Parent Treatment Integrity Checklist

Directions: Following each Fun Chi session record the date and time and place a checkmark on the box that best describes the session

Week 1			
	Day 1	Day 2	Day 3
Date			
Time			
Completed the video in its entirety			
Completed the video partially			
My Child appeared to have fun			
I Had Fun			
My child required minimal assistance			
My child required some assistance			
My child required extensive assistance			

Week 2			
	Day 1	Day 2	Day 3
Date			
Time			
Completed the video in its entirety			
Completed the video partially			
My Child appeared to have fun			
I Had Fun			
My child required minimal assistance			
My child required some assistance			
My child required extensive assistance			
I completed the Social Validity Questionnaire at the end of week 2			

Week 3			
	Day 1	Day 2	Day 3
Date			
Time			
Completed the video in its entirety			

Completed the video partially			
My Child appeared to have fun			
I Had Fun			
My child required minimal assistance			
My child required some assistance			
My child required extensive assistance			

Directions: Following each Fun Chi session record the date and time and place a checkmark on the box that best describes the session

Week 4			
	Day 1	Day 2	Day 3
Date			
Time			
Completed the video in its entirety			
Completed the video partially			
My Child appeared to have fun			
I Had Fun			
My child required minimal assistance			
My child required some assistance			
My child required extensive assistance			
I completed the Social Validity Questionnaire at the end of week 4			

Week 5			
	Day 1	Day 2	Day 3
Date			
Time			
Completed the video in its entirety			
Completed the video partially			
My Child appeared to have fun			
I Had Fun			
My child required minimal assistance			
My child required some assistance			
My child required extensive assistance			

Week 6			
	Day 1	Day 2	Day 3
Date			
Time			
Completed the video in its entirety			
Completed the video partially			
My Child appeared to have fun			
I Had Fun			
My child required minimal assistance			
My child required some assistance			
My child required extensive assistance			
I completed the Social Validity Questionnaire at the end of week 6			

APPENDIX E

RESEARCHER TREATMENT INTEGRITY OBSERVATION CHECKLIST

Researcher Treatment Integrity Observation Sheet

Observations:					
	Family 1	Family 2	Family 3	Family 4	Family 5
Date					
Time					
They completed the video in its entirety					
They partially completed the video					
The child appear to have fun					
The parent(s) appeared to have Fun					
The video appeared to be used as intended					
The child required minimal assistance					
The child required some assistance					
The child required extensive assistance					
The parents completed the Parent Integrity Checklist					
If observation occurred on the last day of the 2nd, 4th, or 6th week, the parent(s) completed the Social Validity Questionnaire					

APPENDIX F

CHARGE SYNDROME DEMOGRAPHICS SHEET

**CHARGE Syndrome
Demographics Sheet**

Subject #

1. Are you the child's:
 - MOTHER
 - FATHER
 - GUARDIAN
 - OTHER: _____

2. Child's Date of Birth (**Month/Day/Year**): _____/_____/_____

3. Child's Gender:
 - MALE
 - FEMALE

4. At what age was your child diagnosed as having CHARGE?
 - BEFORE AGE 1 ____ MONTHS
 - AFTER AGE 1 ____ YEARS OLD

5. Who made the diagnosis of CHARGE?
 - GENETICIST
 - FAMILY PHYSICIAN
 - NEONATOLOGIST
 - ENT
 - OTHER: _____

6. Has your child been tested for the *CHD7* gene mutation?
 - NO (Skip to item 7)
 - YES
 - Did your child test positive or negative for the mutation?
 - POSITIVE
 - NEGATIVE

To your best recollection, when was your child tested?

(Month/Year) _____/_____

7. CHARGE Characteristics your child displays: **(Check all that apply)**

- Coloboma of the eye
- Choanal atresia or stenosis
- Cranial Nerve Dysfunction/Anomaly
- CHARGE outer ear
- CHARGE middle ear
- CHARGE inner ear
- Vestibular Problems
- Heart Defects
- Cleft lip +/- cleft palate
- TE (Tracheosophageal) fistula
- Kidney/Renal Abnormalities
- Genital Abnormalities (Hypoplasia)
- Growth deficiency
- Typical CHARGE Face
- Palm crease (hockey-stick palmar crease)
- Obsessive-Compulsive Behavior or Perseverative Behavior

8. Check all of the following that produce pain for your child? **(Check all that apply)**

- Migraine
- Abdominal Migraine
- Jaw Pain
- Surgery Pain
- Ear Infections
- Sinus Infections (sinusitis)
- Gastroesophageal Reflux
- Constipation
- Hip Pain
- Back Pain
- Muscle Pain
- Stoma Pain
- Tactile Defensiveness
- Other: _____

9. How many surgeries has your child had? _____ Surgeries

10. How does your child eat? **(Check all that apply)**

- EATS BY MOUTH

TUBE FEEDING

11. Is your child walking?

NO (Skip to item 12)

YES → My child walked at _____ years of age

12. Does your child have musculoskeletal problems?

NO (Skip to item 13)

YES



Check all that are applicable

Scoliosis

Flat feet

Cervical fusions

Osteoporosis

Low muscle tone

Increased joint laxity or hypermobility

OTHER: _____

13. Does your child have problems with sleep?

NO (Skip to item 14)

YES



What sleep problems does your child display?

DIFFICULTY FALLING ASLEEP

DIFFICULTY STAYING ASLEEP

SLEEP BREATHING PROBLEMS

TEETH GRINDING IN SLEEP

PAIN DURING SLEEP

OTHER: _____

14. How well does your child see? (**with glasses or contact lenses, if used**)

LEFT

RIGHT

NORMAL VISION

SOME TROUBLE
SEEING

MODERATE
DIFFICULTY

MUCH DIFFICULTY

TOTALLY BLIND

15. How well does your child hear? (**with hearing aids or other hearing devices, if used**)

LEFT	RIGHT	
<input type="checkbox"/>	<input type="checkbox"/>	NORMAL HEARING
<input type="checkbox"/>	<input type="checkbox"/>	SOME TROUBLE HEARING
<input type="checkbox"/>	<input type="checkbox"/>	MODERATE DIFFICULTY
<input type="checkbox"/>	<input type="checkbox"/>	MUCH DIFFICULTY
<input type="checkbox"/>	<input type="checkbox"/>	TOTALLY DEAF

16. My child's communication skills are best described as: (adapted from HomeTalk)

- Makes reactions or noises or behaviors which I need to interpret, and that are difficult for an unfamiliar person to understand.
- Uses behaviors such as gestures, sounds, and body movements which most people can interpret or understand.
- Uses single words, signs, pictures, symbols, or object symbols to represent basic needs.
- Uses some 2 to 5 word phrases and sentences using speech, signs, picture symbols, etc.
- Uses verbal or sign language in complete sentences.

APPENDIX G

PARENT SUGGESTIONS

Parents provided invaluable data regarding specific aspects and procedures to improve in the video. Given that children with CHARGE syndrome often times have some degree of vision impairment, it is imperative that these visual suggestions provided by parents be implemented in a next version of Fun Chi. Parent suggestions include:

- Increasing the visual contrast between the instructor and the background
- Using bright colors to accomplish the contrast between the instructor and the background
- Removing visually distracting stimuli such as a cat that approaches the instructor as she is teaching the Fun Chi forms
- Ensuring the video takes over the entire screen and not just a vertical portion of the screen
- Possibly decreasing the length of some portions of the video (i.e. warm up or punch the polar bear).
- Keeping language used as simple as possible
- Adding sign language and closed captioning to the video
- Including more versions of the Fun Chi video

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