12-1995

Music Therapy and Rett Syndrome: A Survey of Music Therapy Practitioners

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MUSIC THERAPY AND RETT SYNDROME: A SURVEY OF MUSIC THERAPY PRACTITIONERS

by

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A Thesis
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Master of Music
School of Music

Western Michigan University
Kalamazoo, Michigan
December 1995

ACKNOWLEDGEMENTS

I would like to thank Professor Brian Wilson, Professor Susan Gardstrom, and Dr. David Sheldon for your dedication and patience in helping me through this process. I am genuinely honored to have had the opportunity to work with each of you.

A special thanks to all the music therapists who participated in this study, especially to Kathleen Coleman, Michele Schumacher, and Dr. Mary Ellen Wylie for your time spent in reviewing my questionnaire. Your willingness to share your knowledge and experience has made this research possible.

I would like to express my sincere gratitude to Sherry Lepird for your computer expertise and ever giving kindness.

To my parents Larry and Sue and my sister Melinda, I thank you for your unconditional love and support throughout my life. You are truly the "Wind Beneath My Wings."

To my soon-to-be husband, Jeffrey Scott Reno, I owe a great deal to your continued support, encouragement and love. You are my strength and my best friend. I look forward to years of your healing hugs. I also extend my thanks to Barb, Bernie, and Steve Reno for your concern, interest, and love.

Finally, I dedicate this thesis to the loving memory of my sister, Beth Michele Gay, who taught me that life is beautiful and precious. I also dedicate

this to Crystal, Kayla, Amanda, and to the loving memory of Tara Fay Latture. All of you have opened my eyes to Rett syndrome and to the magic that music holds.

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Music therapy practitioners residing in the United States and known to have experience with Rett Syndrome were surveyed to better understand how music therapy aids in the treatment of clients with Rett syndrome. The survey was designed to learn if there were general trends in goals/objectives addressed, session structure used, vocal response to music intervention, strategies toward encouraging independent hand usage, and preferred instruments and adaptive equipment.

Of the 73 sent out to NAMT and AAMT members, 36 questionnaires were returned. Question items that received a 50% or higher response rate by the participants included session structure involving a set routine with improvisation, music intervention as the most beneficial when their clients were upset, change of facial affect when a song was recognized, gentle restraining of one hand, client preference for playing an instrument and for very rhythmic music, therapists' preference for live music and use of voice, and eye gaze for choice making.

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CHAPTER I

INTRODUCTION

Rett syndrome is a neurological disorder found only in females. The disorder involves four stages in which the girls'/womens' cognitive functioning level, hand usage, and ability to communicate are affected. Dr. Andreas Rett (as cited in Lauzon), founder of the syndrome in 1965, believes that for clients with Rett syndrome information is most easily received and comprehended through the use of music.

Music therapy has been utilized with clients with Rett syndrome since 1972 and is supported by the International Rett Syndrome Association (International Rett Syndrome Association, 1987). Music therapy has successfully addressed goals such as improved hand usage, interaction, communication, mobility, and relaxation (Coleman & Hadsell, 1988).

The documentation concerning Rett syndrome and music therapy is minimal and is based primarily on case studies. To date no comprehensive survey circulated to music therapists working with clients with Rett syndrome was found. Consequently, several questions are left unanswered. Are there general trends in the music therapy techniques used by music therapists across the United States? Are there similarities pertaining to goals/objectives addressed and the structure used in sessions? Will there be consistent

responses to music intervention? Are there common strategies to encourage hand usage? What is the preferred choice of instruments and adaptive equipment used in sessions?

Statement of the Purpose

The purpose of this study is to survey all known music therapists residing in the United States who have clinical experience with clients with Rett syndrome to better understand how music therapy aids in the treatment of girls/women with Rett syndrome.

Assumptions

This study assumes that all known music therapists in the United States who have had experience with girls/women with Rett syndrome were contacted and asked to respond to the survey. It also assumes that there has not been a comprehensive survey previously conducted in the United States of music therapists who work with clients with Rett syndrome.

CHAPTER II

REVIEW OF RELATED LITERATURE

Rett Syndrome

Rett syndrome is a progressive neurological disorder which to date has been diagnosed in all ethnic groups but has only been found in girls (Sekul & Percy, 1992). Its cause is unknown (but is thought to be linked to the X chromosome) and it affects approximately 1 in 10,000 live female births (Kerr, 1989). The syndrome was first recognized by Dr. Andreas Rett in 1965 but was not widely known until 1983 when Dr. Rett and Dr. Bergt-Hagberg collectively presented their findings of the syndrome in the American Neurology Journal (Lindberg, 1991).

Girls/women with Rett syndrome have an apparent normal birth and psychomotor development up to age 6-18 months at which point a slowing down or regression is seen in their development (Rett, 1986; Lindberg, 1991). This regression marks the beginning of the first of four stages of Rett syndrome. Because the disorder is based solely on clinical symptoms and a pattern of progress (Sekul & Percy, 1992), a set of diagnostic criteria (See Appendix A) has been developed by the Rett Syndrome Diagnostic Criteria Work Group (1988). Some of the essential criteria include a normal prenatal and

perinatal phase, loss of purposeful hand usage, emergence of stereotypic hand movements (i.e., hand wringing, mouthing), social withdrawal and gait apraxia (Rett Syndrome Diagnostic Criteria Work Group, 1988). In an attempt to further define the syndrome, Dr. Ingred Witt-Engerstrom and Professor Bergt-Hagberg outlined the four stages of the disorder (See Appendix B) and provided common differential diagnosis for Rett syndrome (Rett Syndrome Diagnostic Work Group, 1988). This information has proved to be an important tool for clinical assessment, documentation, and research (Engerstrom, 1990).

Stage one is known as the "Early Onset Stage" and occurs between six to eighteen months of age. Characteristics include hand waving or clapping, stagnated psychomotor development, and inactivity with increasing lack of attention. Stage two is the "Rapid Destructive Stage", which occurs from between 1 to 4 years of age. The girls regress and lose acquired skills, demonstrate autistic tendencies, show general developmental deterioration, display severe dementia, lose speech and functional hand usage (hand clapping/ wringing becomes more prominent) and become uncoordinated. The "Plateau Stage" is the third phase which occurs from 2 to 10 years of age. During this time, the girls' autistic features diminish, development stops regressing, seizures often begin and gross motor abilities are still preserved, but slowly degenerate. The fourth and last stage is the "Late Motor Deterioration Stage" which occurs from 5 years on. During this stage, the girls often become non-ambulatory, have improved emotional contact, seizures become less problematic (easier to

control with medication), gross motor skills deteriorate more rapidly, and weakness, spasticity and severe scoliosis are common.

Both classical and atypical Rett syndrome are symptomatically determined between 2 and 5 years of age. For a diagnosis of classical Rett syndrome, all necessary and supportive criteria must be met (See Appendix A). The diagnosis of atypical Rett syndrome is given to those girls who fulfill all the necessary criteria but not all of the supportive criteria. If any exclusion criteria are met, the Rett syndrome diagnosis is not given (Sekul & Percy, 1992).

According to Rett and Harding, Tudway & Bruyn (as cited in Zapella, 1986), progressive brain damage is evident throughout the four stages, from a clinical as well as neuropathological point of view. It is also a main source of symptoms and final dementia. As with many aspects of Rett syndrome, life expectancy is unknown. The life span appears to be diminished (i.e., death occurs in many clients beginning in childhood) but living into adulthood can be expected by most (Sekul & Percy, 1992).

Cognitive Functioning and Communication

Intellectual level and cognitive functioning are difficult to determine in girls/women with Rett syndrome but are usually believed to be in the severely to profoundly impaired range (Woodyatt & Ozanne, 1992). Kerr (1989) thinks that intellectual understanding is at least at the 12 month level. Using Piaget's

sensorimotor intelligence scale Olsson and Rett (as cited in Lindberg, 1991) discovered that most girls rarely placed higher than stage four. Characteristics of stage four of the sensorimotor intelligence scale include trying out schemes for effect on the environment; intentional behavioral; anticipation of events not dependent on own immediate behavior; and ability to distinguish between self, other people, and the world (Scarr, Weinberg, & Levine, 1986). In reference to this scale, Lindberg (1991) makes the point that Piaget's focus is on motor ability which is often limited in those with Rett Syndrome. "Their intellectual level is not necessarily the same as or reflected by their functioning level" (Lindberg, 1991, p. 61).

Woodyatt and Ozanne (1992) feel that the cognitive impairment of these females may be responsible for the lack of development concerning intentional communication. In 20 girls who were in stages two and three of Rett syndrome, Budden, Meek, & Henighan (1990) reported communication regression at an 8 to 12 month level with no further regression observed in stage four. This implies that intentional communication may be present because in normal development this happens at 9 months of age (Bates & McLean as cited in Woodyatt & Ozanne, 1992). Communication is primarily nonverbal and is demonstrated through various actions including: bodily responses to requests (i.e. "touch," "stand up"); vocalizations which may convey contentment, happiness, anger, or frustration; facial expressions; walking toward desired objects or events; direct selection through eye gaze or touching;

and choice making through the use of pictures (Murphy, 1989; Woodyatt & Ozanne, 1992). Communication is also evident through eye contact or gaze, which appear to occur the same way their hands are used, that is a momentary movement they successfully complete before their stereotypical movements manifest themselves again (Hanks, 1986).

In a study of 6 girls with Rett syndrome, Woodyatt and Ozanne (1992) found all participants to be at the preintentional level of communication. At this level the caregiver assigned a meaning to the childs' action (e.g., "you want a drink") but there was no expectation from the child of a response from the caregiver. In this study the interactional skills appeared to have regressed and responses to social contacts were inconsistent with little eye contact and no seeming awareness of others. Four out of the 6 participants did "enjoy music" (p. 165) and seemed to recognize favorite songs as observed through smiling, increased levels of activity and hyperventilation. Habitual behavioral patterns observed included "undirected vocalizations, bruxism (teeth grinding), and gazing at objects, surroundings and/or persons" (p. 166). Communication of pain was also observed and was inferred from crying.

Woodyatt and Ozanne (1992) believe that before appropriate communication programs can be devised for persons with Rett syndrome, functional and intentional communication levels must be determined. They also feel that the primary focus of therapy should be on training caregivers to recognize the intent of behaviors not usually identified as communication. In reflecting upon

all the possible methods of communication, Rett (1986) believes that the primary means for social contact is through the eye gaze.

Motivation

Motivation plays an important part in the communication of girls/women with Rett syndrome. Through observation of 34 females with Rett syndrome, Zapella (1986) found that stereotypic hand patterns could be notably decreased if there was a strong interest in a given activity such as stories, music and face to face interaction. Zapella feels that the hand patterns are an internal motivational conflict between two "major systems." System A involves "inhibited intention movements" (beginning movements of full behavior, i.e., opening and closing hands) and system B consists of "redirected movements" (attack movements directed towards anything but the opponent, i.e., biting one's lip). The motivational conflicts between systems A and B lead to movements belonging to system C which consists of "displacement activities" (stereotypic hand patterns). Rett (as cited in Webb, 1985) believes that it is a difficult task for the girls/women to learn motivation. There must be a need (directed toward certain goals), a want, and then a craving. Rett suggests the use of musical instruments to connect these concepts. A need is created with the realization that when an instrument is grasped, sound is made. From this initial incident there becomes a want to hear the sound, followed by a craving to grasp the instrument and hear it.

Music Therapy

Despite the limited level of communication associated with persons with Rett syndrome, one avenue that appears to promote interaction and motivation is music. Music therapy has been used with girls/women with Rett syndrome in Europe since 1972 and has been supported by the International Rett Syndrome Association as a means of communicating and reducing stereotypic hand patterns (International Rett Syndrome Association, 1987). Since the "music center is found in the primitive part of the brain which is preserved in these girls", Rett (as cited in Coleman, 1987, p. 2) believes that information is more easily received and comprehended through music. Supporting this theory, Brodeur (1989) explains that the rhythmic and melodic components of music require no abstract thought, thus the ability of the girls with Rett syndrome to understand and perceive rhythm may at times be the only avenue to social communication.

Music therapy has been found "vital" (Hanks, 1986, p. 250) in keeping girls/women with Rett syndrome in contact with the environment. For example, the use of musical instruments appears to increase the level of awareness and responsiveness, thus motivating the girls/women to physically and emotionally reach out (Hanks, 1986). Music therapy also creates a trusting and non-threatening atmosphere for learning because it is success oriented and is built from the rapport established between client and therapist (Coleman, 1989).

Wesecky (1986) found music therapy to be a successful intervention because no response from the client would receive a negative consequence and concepts could be introduced and reviewed in various ways without becoming monotonous. Through his experience, Wesecky believes that the repetition of acoustical stimuli is perceived as a structural pattern. That this stimulation eventually becomes familiar thus producing anticipations and tensions, resulting in relaxation.

Music therapy captures interest. This is marked by an alert sate that is present in most females with Rett syndrome when rhythms and sounds are presented (Kerr, 1989). As a parent of a girl with Rett syndrome, Allan (Brochure) believes that music therapy holds "unlimited potential" (p. 8) and treats the entire child by receiving whatever she gives. She stresses the importance of the therapist adapting to the needs of the individual and listening verbally and nonverbally to the child. Lieb-Lundell (1988) also supports these concepts and believes that it is the therapist's responsibility to work with clinical changes, to instruct parents and teachers in handling the girls, and to have a thorough understanding of the stages and the obstacles that may emerge in each client with Rett syndrome.

The literature reveals that the goals of music therapy with girls/women with Rett syndrome focus primarily on communication and include: (a) promoting appropriate hand usage within structured activities, (b) improving eye contact and social interaction, (c) developing simple communicative responses,

(d) developing basic understanding of cause and effect relationship, (e) encouraging relaxation, and (f) to maintain and/or improve mobility (Coleman & Hadsell, 1988, Coleman, 1989).

Development of communication through the use of music therapy was observed in a girl with a controversial diagnosis of Rett syndrome (Postacchini et al., 1993). She moved from a pre-symbolic stage to one that was "at times more symbolic and less regressed" (p.31). In this situation music therapy appeared to be an influential intervention to improved communication.

Coleman (1989) observed many positive responses to music therapy through her own experience with four girls with Rett Syndrome (ages 5-20, stages two & three). Increased smiling, alertness, activity, animation, head turning to locate sounds, time spent in instrument manipulation, and hand usage were observed during music therapy interventions over a period of 2 1/2 - 9 years. Cerro (1989) found improvement in eye contact (i.e., looking at self and therapist in the mirror), eye gazing (e.g., choosing pictures) and hand usage (i.e., requesting to play more by touching therapist's hand) over 1 1/2 year time span with her 3 1/2 year old client.

Possibly due to the small number of girls diagnosed with Rett syndrome and the recent awareness of the disorder, the published research in music therapy and Rett syndrome has consisted primarily of case studies. One such case study, conducted by Wigram (1991), focused on an 11 year old girl with Rett syndrome. The study measured the effect of session structure and lasted over

a 22 month period. Initially, the sessions were very structured and contained individual activities that were planned for a specific amount of time. This structured music therapy phase lasted for 8 months and focused primarily on hand usage, attending, and expressive communication. During the second music therapy phase, which lasted 14 months and was less structured, the client had begun to develop a musical and personal relationship with the therapist. The sessions were no longer focused on learning appropriate behaviors but rather using those learned behaviors to express feelings and emotions. Improvements in the client's ability to express feelings, interact with the therapist, develop physical dexterity, understand boundaries and maintain and establish a relationship with the therapist were noted during the second phase.

Another case study by Schumacher (1994) focused on interrupting stereotypic hand patterns through specific music therapy interventions. A tone bar, a drum or a woodblock was placed in front of the participant with Rett syndrome. The researcher then set the tempo with a metronome (quarter note equalling 60), sang the song Feel The Tone Bar, and played the instrument that was placed in front of the women with her (the researcher's) right hand. With the researcher's left hand, the participant's hands were separated and placed on the vibrating instrument. The amount of time the participant's hands remained in contact with the instrument was recorded. Schumacher found that "a steady, predictable, rhythmic input and tactile vibration had some variable positive effect on stereotypic hand patterns and did interrupt patterns

for varying lengths of time" (p. viii).

Webb (1985) feels that rhythm instruments encourage visual tracking and touching to feel vibrations. Hand movements have been observed to temporarily lessen when using instruments such as the piano, bodhran, and wind chimes (Montague, 1990). Montague incorporated repetitive hand movements into music by placing a drum or stringed instrument strategically so that the hand movements could come into contact with the instrument. When the girls/ women realized that their movement created a sound, it was the initial step of a communicative interaction with the therapist (Montague, 1990).

Rett (as cited in Lauzon) suggests the use of the cymbal or the gong because it encourages hand usage for deliberate reaching, uses fingertips and palms to feel vibration; improves the looking and following movement; and increases sensitization to vibrations. Lauzon found his 3-year-old client with Rett syndrome to be very attentive and interested when engaged with the cymbal or the gong. These instruments, as well as vocal activities, were also carried out at home by the client's mother. In addition, Lauzon experimented with tuning forks (Pythagorean fifth) and found that they had a calming effect on his client as evidenced by a cessation of handwringing and a satisfied type of vocalization (Lauzon).

In motivating her 11-year-old student with Rett syndrome to purposefully reach out and manipulate, Budash (1989) found the xylophone and tambourine very effective. Rett (as cited in Lauzon) also recommends using the

electric organ to improve independent finger control and conscious movement and feels that utilizing and alternating a variety of instruments is as important as being consistent with the opening structure (i.e. rhythmic and familiar tune) of the music therapy session.

Other researchers have observed positive responses to music therapy intervention such as improved ability to activate a switch independently, increased recognition of the music therapist and peers, improved use of hands to play instruments, improved alertness and involved and improved self feeding skills (Bat-Haee, 1994; Coleman, 1987). Girls/women with Rett syndrome have been able to recognize favorite songs as indicated by smiling, increased levels of activity and hyperventilation. They have appeared to be receptive and discriminating towards musical sounds (Coleman, 1989; Woodyatt & Ozanne, 1992). Increased vocalizations have been noted when the clients were sung to or when music was played. In addition, increased attending, improved grasping, activating a switch or keyboard, improved balance, improved facial expression, and improved vocal interval range have also been observed throughout music therapy interventions (Postacchini et al., 1993; Webb, 1985).

Robbins and Robbins (1994) used an improvisational music therapy approach to increase physical and emotional communication with females with Rett syndrome. Improvisationally based music therapy strives to "reach the music child which has memory, tastes, associations, some level of musical intelligence, feels structure and responds to rhythm" (p. 9). Improvisation in this

study involved incorporating physical (i.e. rocking, playing instruments) and vocal (i.e., singing intervals and patterns) expressions provided by the clients and placed them into the structure of music, thus allowing them to create their own music. In order to avoid any previous associations, the music used during improvisation was largely modal and unfamiliar to the clients. According to the authors improvisational based music therapy was able to help a client who was having difficulty in school, becoming isolated, acting very somber, and had begun to self-mutilate. Her sessions in music therapy focused on building a positive relationship. This developed through the use of her voice as she became aware that she could express and "exchange" (p. 6) feelings with others. In the improvisation situation she was able to use these newly acquired interactions to vent feelings that were acknowledged by the music therapist. After three years of weekly music therapy sessions, she emergenced as a "calm, trusting, and contented" (p. 7) young woman. This change was observed by the school staff as well as the music therapist. Robbins and Robbins believe the improvisational approach is effective because the girls/womens limitations are not the primary focus, but rather the focus is on the person inside (Robbins, 1994).

To the fullest extent possible, Montague (1990) noted that the vocal sounds produced by the girls/women should be used to encourage verbal interaction. In doing this it was thought that the client would become aware of her own sound and would initiate "conversation" at her level.

Music therapy was listed as an option for preventing episodes of hyperventilation and distress in a survey by Sansom, Krishnan, Corbett & Kerr (1993). The parents of daughters with Rett syndrome answered a questionnaire that focused on mood changes and behavioral problems. The researchers found that 76% of the 107 girls with Rett syndrome experienced brief episodes of anxiety as evidenced by hyperventilation, self-injury, frightened expression and general distress. The strategies used to reduce the anxiety included holding, singing, and playing slow music.

Rett (as cited in Webb, 1985) believes that the rate of progress is not determined by number of hours in music therapy, but by how music therapy objectives are incorporated into everyday living. Wesecky (1986) supports this premise by encouraging parents to be trained to use basic music therapy techniques at home, although he also feels that regularity of sessions is necessary for effective treatment. In addition to the above mentioned strategies for effective intervention, Rett (as cited in Lauzon) feels that beginning therapy should be initially done on an individual basis with the gradual addition of other people with whom the girls/women are familiar. Rett (as cited in Webb, 1985) also believes that in order for music therapists to effectively encourage musical interaction, the therapists' music theory skills need to be solid. The ability to present and anticipate musical tensions and resolutions determine the effectiveness of the intervention.

Music therapists address goals in a variety of settings that may include:

individual, self-contained groups, and mainstreamed or full inclusion situations. Regardless of the setting, the questions following should be considered in order to increase the possibility of a positive intervention: (a) Are these functional goals and objectives? (b) Are these goals and objectives important to the family? (c) Are these activities age appropriate? (d) Are activities reflective of the girls/womens preferences? and (e) Are the strategies used to increase their participation in integrated and community settings (Coleman, 1990)?

Based on existing literature, it appears that music therapy is an established and highly effective intervention for girls/women with Rett syndrome. No documentation was found that summarizes music therapy practices by United States music therapists toward females with Rett syndrome. The purpose of this study is to determine if there are: (a) general trends of music therapy techniques used by music therapists, (b) similarities pertaining to goals/objectives addressed and session structure used, (c) universal tendencies of the girls'/womens' vocal and non-vocal response to music intervention, (d) common strategies used to encourage hand usage, and (e) preferred instruments and adaptive equipment used.

Statement of Hypotheses

The hypotheses of this study are as follows:

1. There will be no discernible trends in the respondents' stated goals/objectives for females with Rett syndrome (as measured by questions 1 & 2 of

the questionnaire).

2. There will be no discernible trends in the respondents' stated session structure for females with Rett syndrome (as measured by questions 3-5 of the questionnaire).

3. There will be no discernible trends in the respondents' stated vocal response of females with Rett syndrome (as measured by questions 6-10 of the questionnaire).

4. There will be no discernible trends in the respondents' stated non-verbal response of females with Rett syndrome (as measured by questions 11 & 12 of the questionnaire).

5. There will be no discernible trends in the respondents' stated hand usage of females with Rett syndrome (as measured by questions 13-16 of the questionnaire).

6. There will be no discernible trends in the respondents' stated musical instruments used with females with Rett syndrome (as measured by questions 17-21 of the questionnaire).

7. There will be no discernible trends in the respondents' stated adaptive equipment used with females with Rett syndrome (as measured by 22-25 of the questionnaire).

Limitations of the Study

A limitation of the study was that not all literature on Rett syndrome

may have been acquired. Dr. Rett is Austrian and many of his articles, as well as other articles authored by professionals who have documented research in this area, are not printed in English.

A limitation of the study was that answers to the questionnaire had to be generalized if music therapists had experience with more than one female with Rett syndrome. This forced generalization may have influenced the results.

A further limitation of the study was the possibility of respondents' answering questions from experience other than their own or responding to answers as they think they should. This may have had an effect on the percentage outcomes.

A final limitation was the small number of participants thus reducing the validity of the study. This could be due to the length of the survey or to the fact that those who didn't respond did not have experience with persons with Rett syndrome. Also because of the small "n", the Results of this study may not be generalizable to all females with Rett syndrome.

CHAPTER III

METHOD

Participants

The investigator contacted the National Association for Music Therapy and the American Association for Music Therapy for lists of music therapists who had reported working with girls/women with Rett syndrome in 1995. An initial list of 29 names was generated. Some of those on the list were contacted by telephone for networking purposes. Ultimately a list of 68 potential participants was developed. Each person was then sent a demographic survey which included a request for any additional names and addresses of music therapists known to be working with girls/women with Rett syndrome. Only music therapists who were Registered or Certified and had at least two months clinical experience with girls/women with Rett syndrome were selected to participate.

Instruments

Two instruments designed by the investigator were used in this study. A demographic survey (see Appendix C) was used to determine music therapists' background and experience with girls/women with Rett syndrome. Questions

were designed to provide information regarding credentials, length of time as a practicing music therapist, length of involvement with and number of girls/ women as clients, and information on how music therapy sessions were structured (i.e. scheduling, length of sessions, other therapists involved in the sessions, session setting, and involvement with current issues concerning Rett syndrome). The last two questions solicited information about effective music therapy interventions and requested names and addresses of other known music therapists working with girls/women with Rett syndrome.

A questionnaire (see Appendix D) was used to determine consistencies of music therapy techniques and observed responses by the girls/women to music. A cover letter (see Appendix C and D) was sent with each demographic survey and questionnaire. The questions were based on various music therapy and Rett syndrome literature and the investigator's clinical experience. The first two sections of questions were designed to determine goals and objectives and session structure. The next two sections looked at the vocal and non-verbal response of the girls/women in relation to musical stimuli. The last three sections were designed to gain information concerning approach to hand usage during sessions, musical behavior and preferences of the girls/women and the therapist and adaptive procedures used. The questionnaire was reviewed by the thesis committee and checked for content validity by three music therapists, with considerable experience and expertise with girls/women with Rett syndrome, before being sent to the participants.

Consent and Approval

This research project required approval from the Western Michigan University Human Subjects Institutional Review Board. The Human Subjects Approval Form (see Appendix E) was completed and then reviewed by a sub-committee of the Board and found to be exempt. The research project was approved and the principal investigator was formally notified of this decision (see Appendix E).

Design and Procedures

Sixty-eight music therapists who were thought to have experience working with girls/women with Rett syndrome were recruited to participate in this study. These individuals were sent a cover letter, a stamped return envelope and a demographic survey which included a request for other known music therapists working with this population. When the surveys were returned the names of the participants were crossed off the demographic survey list. Out of the 68 surveys 52 were returned. Of those respondents, 4 of the participants did not work with females with Rett syndrome and 2 were returned because of incorrect addresses. Sixteen people did not respond.

Forty-six cover letters, stamped return envelopes and questionnaires were then sent to those who had responded. Sixteen demographic surveys and questionnaires were sent to those who did not respond and to the nine new

participants (see Appendix F), for a total of 73 possible participants. The return of the completed demographic survey and the questionnaire was assumed to indicate informed consent to be a participant in the study.

Of the 29 surveys/questionnaires that were returned, 24 were usable. A follow-up letter (see Appendix G) was sent two weeks later to those individuals who had not responded to either the demographic survey or the questionnaire. This letter encouraged the participants to return their surveys and included another copy of the questionnaire and stamped return envelope. A total of 36 were generated.

Analysis

Response rates for each item were tabulated by indicating the percentage and number of respondents who selected each alternative for each item. All items that included a ranking scale were analyzed for the most frequent response. In addition, relationships between specific variables (i.e., length of time working with clients with Rett syndrome and number of clients with Rett syndrome worked with throughout career with response to therapists' singing and methods of choice making, positive response to tempo/dynamics, and adaptive equipment used) were also compared. Trends were defined as those questions receiving 20% or greater response. Word Perfect 5.1 and the Statistical Package for the Social Sciences were used to analyze the data.

CHAPTER IV

RESULTS

Of the 73 questionnaires sent out a total of 46 (63%) were returned. Of those returned, 36 (49.3%) were useable (i.e. both the demographic survey and the questionnaire were returned) for the data analysis. The 36 participants were from the following states: California (4), Florida (1), Indiana (3), Maryland (1), Massachusetts (4), Michigan (1), Minnesota (1), New York (4), Ohio (3), Texas (9), Virginia (2), and Wisconsin (3). Ten of the returned questionnaires/surveys were not useable because the respondents either: (a) did not work with females with Rett syndrome, (b) felt they did not have adequate experience with the Rett syndrome population (c) their work with clients with Rett syndrome was not recent, (d) they did not presently work with clients with Rett syndrome, or (e) surveys were returned due to incorrect addresses. Twenty-seven questionnaires/surveys were not returned.

Demographic facts were collected to provide information about credentials, involvement with females with Rett syndrome, and how music therapy sessions were conducted. As can be seen in Table 1 the highest academic achievement of the majority of the respondents (63.9%, N=23) was a Bachelor's degree. A Master's degree was obtained by 33.3% (N=12) and a Doctoral degree by 2.8% (N=1). Over half of the participants were Registered

Table 1

Highest Degrees Held by Respondents

Degree	Major	n	Percentage
Bachelor's Degree (63.9%, n=23)	Music Therapy Music	21	91.3%
	Education	-	-
	Equivalency	1	4.3%
	Other	1	4.3%
Master's Degree (33.3%, n=12)	Music Therapy	4	33.3%
	Music Education	1	8.3%
	Equivalency	1	8.3%
	Other	6	50.0%
Doctoral Degree (100.0%, n=1)	Music Therapy/Education	1	100.0%
	Other		-

Note: The Symbol (-) indicates no ranking

Music Therapists with Board Certification (see Table 2).

The majority of participants had been practicing music therapists (58.3%, n=21) for 8 or more years (see Table 3) and had worked with females with Rett syndrome 25% (N=9) of the time (see Table 4). Sixty-four percent (N=23) of the respondents reported that they had worked with one or two clients with Rett syndrome (see Table 5) and 80.6% (N=29) were presently working with one or two females with Rett syndrome (see Table 6).

Half of the respondents stated that sessions were held once a week for

Table 2

Credentials Held by Respondents

Credentials	n	Percentage
Registered Music Therapist (RMT)	10	27.8%
Certified Music Therapist (CMT)	4	11.1%
RMT-Board Certification	20	55.6%
CMT-Board Certification	1	2.8%
CMT-RMT-BC	1	2.8%

Table 3

Length of Time Practicing as a Music Therapist

Length of Time	n	Percentage of Respondents
Less than 1 year	1	2.8%
1 - 3 years	9	25.0%
3 - 8 years	5	13.9%
8 + years	21	58.3%

30 minutes (see Tables 7 and 8). Thirty-nine percent (n=14) conducted individual sessions, 16.7% (n=6) had group sessions, and 44.4% (n=16) had both

Table 4

Length of Time Working With Females With Rett Syndrome

Length of time	n	Percentage of Respondents
Less than 1 year	6	16.7%
1 - 3 years	13	36.1%
1 - 8 years	8	22.3%
8 + years	9	25.0%

Table 5

Total Number of Clients With Rett Syndrome to Have Received Music Therapy Services From Respondents

Number of Clients	n	Percentage of Respondents
1	13	36.1%
2	10	27.8%
3	3	8.3%
4	2	5.6%
5	2	5.6%
6 - 8	3	8.3%
8 - 10	2	5.6%
10 - 12	1	2.8%
12 +	-	-

Notes: the symbol (-) indicates no response

Table 6

Number of Clients With Rett Syndrome With Whom Music Therapists Are Presently Working

Number of Clients	n	Percentage of Respondents
1	18	50.0%
2	11	30.6%
3	2	5.6%
4	-	-
5	-	-
6 - 8	1	2.8%
8 - 10	1	2.8%
10 - 12	-	-
12 +	-	-

Notes: the symbol (-) indicates no response

group and individual sessions. Most of the music therapists surveyed worked alone during sessions (75%, n=27), while 22.2% (n=8) worked with other therapists (physical, occupational).

The respondents reported that music therapy services were provided in a variety of settings with the most frequent being a self-contained classroom (61.1%, n=22). It appears that few music therapists see females with Rett syndrome in a full inclusive situation (see Table 9). In order to keep involved

Table 7

Number of Times Per Week Music Therapy Sessions Are Held

Times Per Week	n	Percentage of Respondents
1	18	50.0%
2	11	30.6%
3	3	8.3%
4	2	5.6%
5	1	2.8%
6	-	-

Notes: the symbol (-) indicates no response

Table 8

Length of Music Therapy Session

Length of Session	n	Percentage of Respondents
15 - 25 Minutes	5	13.9%
30 Minutes	19	52.8%
45 Minutes	8	22.2%
1 Hour	1	2.8%
1 Hour and 15 Minutes +	3	8.3%

Table 9

Setting for Music Therapy Services

Setting for Music Therapy Services	Most Freq.	n	Percentage
Self-contained class	1	22	61.1%
Mainstreamed	4	6	16.7%
Full inclusion	6	1	2.8%
Individual pull-out	2	11	30.6%
Private practice	3	9	25.0%
Other	5	5	13.9%

with current issues concerning Rett syndrome, 61.1% (n=22) of the respondents rely on parent contact and/or 27.8% (n=10) are members of the International Rett Syndrome Association (see Table 10). One quarter (25%, n=9) of those responding reported that they were not involved with Rett syndrome issues.

Hypothesis one, "There will be no discernible trends in the respondents' stated goals and objectives for females with Rett syndrome" was rejected. Question one used a ranking system to determine order of importance of goals and objectives (see Table 11). Hand usage was determined by 33.3% (n=12) of the respondents to be the most important goal/objective addressed. The second most important was choice making (16.7%, n=6) followed by attention

Table 10

Involvement With Current Rett Syndrome Issues

Involvement with Rett Syndrome Issues	Most Frequent	n	Percentage
Not involved	3	9	25.0%
Parent contact	1	22	61.1%
IRSA member	2	10	27.8%
IRSA conference	5	1	2.8%
Local parent groups	5	1	2.8%
Other	4	8	22.2%

span and eye contact (both at 13.9%, n=5). Muscle coordination was the only goal/objective not ranked number one by any respondent and vocal response was ranked number one by only one respondent. All goals/objectives were addressed at some level by music therapists. Question two determined that goals/objectives were addressed 100% (n=36) of the time in areas other then music therapy. The most common area was the educational setting at 88.9% (n=32) with the next most frequent area being the related therapies (physical therapy, occupational therapy, speech therapy) at 77.8% (n=28). Goals/ objectives were also addressed at home by a caregiver 58.3% (n=23) of the time and 16.7% (n=6) were addressed in areas other than those listed.

Hypothesis two "There will be no discernible trends in the respondents'

Table 11

Goals and Objectives Addressed During Music Therapy

Goals and Objectives Addressed	Most Freq.	Mean	n	Percentage
Hand Usage	1	2.771	12	33.3%
Vocal Response	7	5.179	1	2.8%
Cause and Effect	5	4.031	3	8.3%
Muscle Coordination	-	5.161	-	8.3%
Attention Span	4	3.677	5	13.9%
Eye Contact	3	3.273	5	13.9%
Choice Making	2	3.970	6	16.7%
Other	6	2.286	3	8.3%

Note: A mean closer to 1.000 indicates a greater agreement of respondents. The symbol (-) indicates no ranking.

stated session structure for females with Rett syndrome" was rejected. Individual sessions using a set routine with improvisation was the most frequently reported session structure (80.6%, n=29). Group sessions used this pattern 58.3% (n=21) of the time. For both individual and group sessions (see Table 12), the using of a set routine without improvisation or with complete improvisation was infrequent. Sixty-one percent (n=22) of the respondents felt that individual music therapy sessions were the most beneficial session structure for females with Rett syndrome (see Table 13). Only 2.8% (n=1)

Table 12

Group and Individual Session Structure

Session Structure	Individual Sessions		Group Sessions	
	n	%	n	%
Set Routine W/Out Improvisation	2	5.6%	2	5.6%
Set Routine With Improvisation	29	80.6%	21	58.3%
Complete Improvisation	1	2.8%	1	2.8%

Table 13

Preference of Group or Individual Music Therapy Sessions

Preference	n	Percentage
Individual More Beneficial	22	61.1%
Group More Beneficial	1	2.8%
Equally Beneficial	11	30.6%
No Opinion	2	5.6%

believed that group sessions were more beneficial. Thirty-one percent (n=11) felt that individual and group sessions were equally beneficial while only 2.8%

(n=1) believed that group sessions were more beneficial.

Hypothesis three "There will be no discernible trends in the respondents' stated vocal response of females with Rett syndrome" was rejected. Fifty-six percent (n=20) of the respondents stated that vocalization was the most observed response of females with Rett syndrome. No vocal response other than crying or laughing was reported by 52.8% (n=19) of the respondents while primarily vocalization with some intelligible verbalization was observed in 13.9% (n=5) of clients with Rett syndrome. Only 5.6% (n=2) of clients demonstrated intelligible verbalization and 5.6% (n=2) had no opinion (see Table 14). Forty-two percent (n=15) of the respondents felt that females with Rett syndrome increased the amount of vocalizations/verbalizations in response to singing during sessions. Conversely 36.1% (n=13) had observed

Table 14

Verbal and/or Vocal Response of Females With Rett Syndrome

Verbal/Vocal Response	Most Frequent	n	Percentage
Intelligible Verbal	4	2	5.6%
Vocal w/Intelligible	3	5	13.9%
Vocalization	1	20	55.6%
Only Laugh and Cry	2	19	52.8%
No Opinion	4	2	5.6%

no vocal response from their clients while 19.4% (n=7) had observed responses in the clients other than those listed in the questionnaire. Observations of any decrease in the amount of verbalizations and increase in volume range were rarely observed. In addition a decrease in vocal pitch range or a decrease in volume range of voice were not selected by any respondent as the most frequent response (see Table 15).

Forty-four percent (n=16) of the respondents agreed or strongly agreed

Table 15

Most Frequent Reaction of Females With Rett Syndrome to Therapist Singing

Reaction to Therapist Singing	Most Freq.	Mean	n	Percentage
Increased vocalization	1	1.278	15	41.7%
Decreased vocalization	5	2.875	2	5.6%
Increased pitch	4	2.667	2	5.6%
Decreased pitch	-	5.333	-	5.6%
Increased range	6	2.375	1	2.8%
Decreased range	-	3.750	-	-
No vocal response	2	1.833	13	36.1%
Other	3	1.889	7	19.4%

Notes: A mean closer to 1.000 indicates a greater agreement of respondents. The symbol (-) indicates no ranking.

that females with Rett syndrome respond better to tasks when the instructions were sung rather than spoken (see Table 16). However, an equal number (44%, n=16) were unsure and 11.1% (n=4) disagreed. No respondent strongly disagreed with the statement. Fifty percent (n=18) of the respondents felt that music was the most beneficial intervention in promoting a reassuring environment (see Table 17). The item ranked number two was hold/physical touch at 19.4% (n=7) with the third ranking, a preferred or familiar activity, at 16.7% (n=6).

When asked to rank which specific music intervention promoted a reassuring environment, singing a favorite song with accompaniment was found to be the most effective according to 27.8% (n=10) of the respondents. Singing

Table 16

Response to Sung Vs. Spoken Instructions

Opinion	n	Percentage
Strongly Agree	8	22.2%
Agree	8	22.2%
Unsure	16	44.4%
Disagree	4	11.1%
Strongly Disagree	-	-

Note: The symbol (-) indicates no ranking.

Table 17

Interventions Found Beneficial in Promoting a Reassuring Environment

Interventions to Promote a Reassuring Environment	Most Frequent	Mean	n	Percentage
Hold/Physical Touch	2	2.455	7	19.4%
Client Interacts First	-	3.300	-	5.6%
New Activity	6	3.727	1	2.8%
Preferred Activity	3	2.500	6	16.7%
Music Intervention	1	1.444	18	50.0%
Other	4	2.000	4	11.1%
Have Not Experienced	5	2.000	4	11.1%

Notes: A mean closer to 1.000 indicates a greater agreement of respondents. The symbol (-) indicates no ranking.

a favorite song a capella was ranked second at 19.4% (n=7) while improvising music specific to the situation was ranked third at 11.1% (n=3). Eight percent (n=3) found listening to recorded music helpful, while 8.3% (n=3) also found singing a song specific to the situation with accompaniment beneficial (see Table 18).

Hypothesis number four "There will be no discernible trends in the respondents' stated non-verbal response of females with Rett syndrome," was rejected. A ranking scale was used to determine how females with Rett

Table 18

Specific Music Interventions Used to Promote a Reassuring Environment

Music Interventions Promote Reassuring Environment	Most Frequent	Mean	n	Percentage
Sing fav./ A cappella	2	2.087	7	19.4%
Sing fav./ Accomp.	1	2.261	10	27.8%
Sing specific/ A cappella	7	3.353	2	5.6%
Sing specific/ Accomp.	5	3.526	3	8.3%
Improv Instru/ Music spcf	6	4.450	2	5.6%
Improv Vocal/ Music spcf	3	3.636	4	11.1%
Listen to recorded music	4	4.150	3	8.3%
Other	8	2.750	2	5.6%

Notes: A mean closer to 1.000 indicates a greater agreement of respondents.

syndrome respond when recognizing a favorite song (see Table 19). Sixty-eight percent (n=24) of the respondents stated that a change in facial affect was noticed while 16.7% (n=6) have observed their clients leaning forward when recognizing a favorite song. Responses other than those listed were chosen by 11.1% (n=4) of the respondents.

The questionnaire revealed that when waiting for a reaction the most frequently observed response time was 10-30 seconds (41.7%, n=15). The

Table 19

Most Typical Responses of Females with Rett Syndrome in Recognition of Favorite Song/Activity

Recognition of Favorite Song/Activity	Most Frequent	Mean	n	Percentage
Hyperventilating	5	3.706	2	5.6%
Laughing	7	2.870	1	2.8%
Leaning Forward	2	2.414	6	16.7%
Increased Hand Patterns	6	4.188	2	5.6%
Changing Facial Affect	1	1.735	24	66.7%
Vocalizing	4	3.265	2	5.6%
Other	3	3.000	4	11.1%

Note: A mean closer to 1.000 indicates a greater agreement of respondents

second most common response time was from 30 seconds to 1 minute (19.4%, n=7). The response times of 5-10 seconds and 1 to 2 minutes were each reported by 11.1% (n=4) of the respondents. Those respondents having group sessions (5.6%, n=2) differed in response ranging from 15-30 seconds to 2 minutes (see Table 20).

Hypothesis five, "There will be no discernible trends in the respondents' stated hand usage of females with Rett syndrome," was rejected. Grasping instruments was the most frequently used method to encourage hand usage during sessions (33.3%, n=12). Tapping or hitting various instruments were

Table 20

Observed Response Delay in Clients With Rett Syndrome

Response Delay	n	Percentage
5-10 seconds	4	11.1%
10-30 seconds	15	41.7%
30 seconds to 1 minute	7	19.4%
1-2 minutes	4	11.1%
2-4 minutes	2	5.6 %
4 or more minutes	2	5.6%
group-limited wait	2	5.6%

closely ranked with 25% (n=9) and 22% (n=8) respectively. Sign language and methods other than those listed were not ranked 1st by any respondent (see Table 21).

Fifty percent of the respondents stated that more than sometimes or frequently adaptive equipment or procedures were used to encourage independent hand usage. The most frequently used procedure was the gentle restraining of one hand (69.9%, n=23). Thirty-one percent sometimes or rarely used adaptive equipment or procedures and 11.1% never used them (see Table 22).

The most frequently used instrument found effective in whole hand cylindrical grasp was the tambourine (22.2%, n=8). Using a mallet for the tone block, drum, etc. (19.4%, n=7) and manipulating the jingle bells (16.7%,

Table 21

Most Frequent Ways Hand Usage is Encouraged

Ways Hand Usage is Encouraged	Most Frequent	Mean	n	Percentage
Grasping Instruments	1	2.147	12	33.3%
Switch Activating	5	3.524	1	2.8%
Touch Requesting	3	2.783	8	22.2%
Strumming Instruments	4	2.792	4	11.1%
Tapping/Hitting Instruments	2	2.321	9	25.0%
Sign Language	-	5.429	-	-
Other	-	3.000	-	-

Notes: A mean closer to 1.000 indicates a greater agreement of respondents. The symbol (-) indicates no ranking.

n=6) were ranked 2nd and 3rd respectively (see Table 23). Although many respondents did not address the pincer grasp in their (see Table 24), those that did respond found plucking the strings of a guitar or dulcimer to be most effective (30.6%, n=11) (see Table 24).

Hypothesis six, "There will be no discernible trends in the respondents' stated musical instruments used with females with Rett syndrome," was rejected. Seventy-eight percent (n=28) of those that responded stated that their clients with Rett syndrome displayed a preference for playing a favorite (n=6) did not observe any preference and 5.6% (n=2) did not respond. Although

Table 22

Most Frequently Used Adaptive Equipment or Procedures Used to Encourage Hand Usage

Adaptive Equipment and Procedures Used	Most Frequent	Mean	n	Percentage
Elbow Splints	3	1.500	5	13.9%
Hand Mitts	5	1.600	2	5.6%
Gentle Restrain 1 Hand	1	1.179	23	69.9%
Do not use	2	1.778	5	13.9%
Other	4	1.857	2	5.6%

Notes: A mean closer to 1.000 indicates a greater agreement of respondents.

there were no outstanding percentages, the most preferred instrument by females with Rett syndrome was the guitar (16.7%, n=6) (see Table 25). The second ranked instrument was the chime tree (13.9%, n=5) and the third was the omnichord (11.2%, n=4).

An average of 85.78% of music therapists surveyed use live music during their sessions. Forty-two (n=15) percent used live music 100% of the time. Recorded music is not the most preferred choice for music therapists (average of 24% employ it) as only 5.7% of the respondents used it 50% of the time. The voice was the most preferred instrument (61.1%, n=22) used in live music by music therapists. The guitar (16.7%, n=6) and instruments other

Table 23

Most Effective Instruments Used to Promote Whole Hand Cylindrical Usage

Instruments to Promote Whole Hand Cylindrical	Most Frequent Response	Mean	n	Percentage
Maraca	4	2.583	6	16.7%
Mallet	2	2.619	7	19.7%
Cabasa	5	3.000	3	8.3%
Tambourine	1	2.333	8	22.2%
Jingle Bells	3	2.769	6	16.7%
Other	6	2.818	3	8.3%

Notes: A mean closer to 1.000 indicates a greater agreement of respondents.

Table 24

Most Effective Instruments Used to Promote Pincer Grasp

Instruments Used to Promote Pincer Grasp	Most Frequent	Mean	n	Percentage
Melodee Bells	2	1.6000	2	5.6%
Finger Chimes	4	2.250	1	2.8%
Guitar/Dulcimer	1	1.231	11	30.6%
Other	3	2.000	2	5.6%

Notes: A mean closer to 1.000 indicates a greater agreement of respondents.

Table 25

Most Preferred Instruments by Females With Rett Syndrome

Preferred Instruments	Most Frequent	Mean	n	Percentage
Tambourine	5	2.231	3	8.3%
Drum	6	1.857	3	8.3%
Cabasa	8	2.000	2	5.6%
Tone Block	-	-	-	-
Cymbal	-	-	-	-
Omnichord	3	2.300	4	11.1%
Autoharp	-	5.500	-	-
Chime Tree	2	1.429	5	13.9%
Bells	7	2.375	2	5.6%
Maracas	9	2.429	2	5.6%
Guitar	1	1.923	6	16.7%
Piano	-	3.000	-	5.6%
Electronic Keyboard	4	2.444	4	11.1%
Other	10	2.000	1	2.8%

Notes: A mean closer to 1.000 indicates greater agreement of respondents. The symbol (-) indicates no ranking.

than those listed (8.3%, n=3) were ranked second and third (see Table 26). Although some respondents stated that determining musical style/preference was difficult to categorize, those who responded found 41.7% (n=15)

Table 26

Instruments Most Preferred by Music Therapists When Working With Clients With Rett Syndrome

Instruments Preferred by Music Therapists	Most Frequent	Mean	n	Percentage
Piano	6	3.083	2	5.6%
Keyboard	4	3.063	2	5.6%
Guitar	2	2.100	6	16.7%
Omnichord	5	2.538	2	5.6%
Voice	1	1.424	22	61.1%
Other	3	2.000	3	8.3%
Do Not Use	-	-	-	-

Notes: A mean closer to 1.000 indicates greater agreement of respondents. The symbol (-) indicates no ranking.

preferred children's music. Twenty-two percent (n=8) observed music categories other than those listed and 13.9% (n=5) had no opinion (see Table 27).

A Likert scale to determine the positive response of females with Rett syndrome to various types of musical tempos and dynamics. Fifty-six percent (n=20) of respondents strongly agreed that their clients positively responded to very rhythmic music (see Table 28). Thirty-one percent (n=11) reported that they strongly agreed that fluid music received a positive response from their clients with Rett syndrome.

Table 27

Most Preferred Musical Styles of
Females With Rett Syndrome

Preferred Musical Style	Most Frequent	Mean	n	Percentage
Rock	4	2.167	3	8.3%
Easy Listening	-	2.400	8	22.2%
Jazz	-	3.000	-	2.8%
Country	5	2.455	2	5.6%
Reggae	-	3.000	-	-
Children's Music	1	1.636	15	41.7%
Church	-	3.400	-	-
Other	2	1.769	8	22.2%
No Opinion	3	1.000	5	13.9%

Notes: A mean closer to 1.000 indicates greater agreement of respondents. The symbol (-) indicates no ranking.

Hypothesis seven, " There will be no discernible trends in the respondents' stated adaptive equipment used with females with Rett syndrome," was rejected. Forty-seven percent (n=17) of music therapists reported that they offered an instrument choice most frequently during sessions (see Table 29). The option of activity choice was ranked number two by 19.4% (n=7) of the respondents.

Eye gaze was found by 66.7% (n=24) of the respondents to be the most

Table 28

Music That Clients With Rett Syndrome Positively Respond to

Positive Response to Music	Most Frequent	Mean	n	Percentage
Very Rhythmic	1	1.694	20	55.6%
Fluid	2	1.941	11	30.6%
Loud	5	2.629	7	19.4%
Soft	3	2.200	10	27.8%
Fast	4	2.229	10	27.8%
Slow	6	2.206	7	19.4%

Notes: The mean closer to 1.000 indicates greater agreement of respondents. The symbol (-) indicates no ranking.

Table 29

Most Frequently Offered Music Therapy Choices to Females With Rett Syndrome

Choices Offered	Most Frequent	Mean	n	Percentage
Song	4	2.350	5	13.9%
Instrument	1	1.742	17	47.2%
Activity	2	2.263	7	19.4%
Repeat Activity	3	2.609	5	13.9%
Other	-	4.000	-	-

Notes: A mean closer to 1.000 indicates greater agreement of respondents. The symbol (-) indicates no ranking.

effective method to encourage choice making (see Table 30). Touching desired objects was the second most effective method reported (22.2%, n=8). Other listed options were minimally ranked.

Participants were asked to list the type and brand of switch they use with their clients with Rett syndrome (see Table 31). Thirty-nine percent (n=14) reported a type and 33.3% (n=12) listed a brand. Twenty-eight percent of those surveyed did not respond. The most preferred type of switch was the Big Red made by Ablenet.

Table 30

Most Effective Methods Used to Encourage Choice Making

Methods Used	Most Frequent	Mean	n	Percentage
Eye Gaze	1	1.250	24	66.7%
Touching	2	1.793	8	22.2%
Switch	-	2.909	-	-
MIDI electronic devices	4	2.750	1	2.8%
Other	3	2.667	1	2.8%
Never Experienced	-	-	-	-
No Opinion	-	-	-	-

Notes: A mean closer to 1.000 indicates greater agreement of respondents. The symbol (-) indicates no ranking.

Table 31

Most Preferred Type and Brand of Switches
Used by Music Therapists

Most Frequent	Type of Switch	Brand of Switches
1	Big Red	Ablenet
2	Jelly Bean	Ablenet
*	Panel	Ablenet
*	Pedal	Radio Shack
3	Pressure	Homemade
*	Say-It-Switch	Ablenet
*	Talking Rocking Plate	Unknown

Notes: 38.9% named a switch
33.3% do not use switches
27.8% did not respond
The symbol (*) identifies switches only mentioned once.

A variety of adaptive communication devices found useful with this population were also reported (see Table 32). Forty-two percent (n=15) responded to this question, 27.8% (n=10) do not use adaptive equipment, and 30.6% (n=11) did not respond. The Intro Talker was the only item mentioned more than once by the respondents.

Due to the assortment of recommendations for specific resources reported by participants, the responses were broken down into two categories.

Table 32

Adaptive Communication Devices Found Most Useful by Music Therapists Working With Clients With Rett Syndrome

Most Frequent	Adaptive Communication Devices
*	Adapted tape player w/loop tape
*	Beeper Boards
*	Eye gaze frame
1	Intro Talker
*	Letter cards
*	Mayer Johnson picture communication symbols
*	MIDI electronic keyboards and drum pads
*	Photo representation of activities
*	Velcro for instruments
*	Wolf Voca - communication board

Notes: 77.8% provided comments
22.2% did not respond
The symbol (*) represents items only mentioned once.

For resources recommended by music therapists see Table 33. For ideas recommended by music therapists see Table 34. Seventy-eight percent (n=28) of the respondents replied and 22.2% (n=8) did not.

Therapist - client relationships were also examined, i.e. the number of years therapists have worked with females with Rett syndrome (less than 4

Table 33

Recommended Resources by Music Therapists

Specific Resources
Nellie Edge books
Kathleen Coleman visual aid set
"Everyone Can Move" and "Music is for Everyone" by Laurie Farnan and Faith Johnson
"Respiration tape" by O.T.R. Sheila Frick
All information from the International Rett Syndrome Association
Understanding Rett Syndrome by Barbro Lindberg
Raffi books
Steve-n-Greg songbooks and tapes
"The Real Little Classical Fake Book" Hal Leonard Corp

Notes: 77.8% responded with resources and ideas
22.2% did not respond

years, more than 4 years), the number of clients with Rett syndrome they have worked with during their careers (two or less, three or more) and variables including: (a) response to therapist singing, (b) methods of communication, (c) adaptive equipment/procedures used to encourage independent hand usage, and (d) positive response to music.

Table 34

Ideas Recommended by Music Therapists

Music	Movement	Tactile
Original compositions personalizing to client	Marching Music	Use lotion, play-dough, beans, etc.
Make auditory cassette tapes for client to take home	Parachute Activities	Puppets
Music	Movement	Beanbags
Use tapes of the clients' voices	Relaxation	
Use lyric substitution		
Explore different modes and idioms (Middle Eastern, pentatonic)		
Use of drum and rhythm instruments		

Notes: 77.8% responded with resources and ideas
22.2% did not respond

In response to the therapist singing, eleven participants who had worked with clients with Rett syndrome less than four years ranked "no noted response" number one. This contrasts with seven respondents who had worked with clients with Rett syndrome 4 years or more that ranked "increasing vocal response" as number one. The number of clients the respondents worked with during their career affected the ranking of responses. Of those who worked

with one or two clients, twelve ranked "increasing amount of verbalization" number one, followed by number two "no noted vocal response". Those who had worked with three or more females with Rett syndrome ranked "other" first and "no noted vocal response" at a close second.

Only two participants (4 years or more) responded to the "other" category ranking it sixth. This differs from the seven participants working less than 4 years who ranked it number two with a mean of 1.143. Tables 35 and 36 contain further results of this question. Although the primary focus of this question was to determine vocal response to the therapist singing, responses other than those listed on the questionnaire included: (a) visually attending, (b) reaching for therapist face, (c) displaying change in affect, (d) increasing eye contact, (e) turning to look at therapist, and (f) smiling. One respondent stated that her clients' reactions were sporadic and different each time. The physical and affective response of these clients need to be further examined. The only area of some agreement was the decrease in pitch. Three of the four groups (i.e., less than 4, more than 4, one or two, three or more) ranked decrease in pitch last. Those working less than 4 years did not respond.

It appears that there was no overall consistency when comparing the number of years the therapists clinically worked, the number of clients serviced during the therapists' career and response to the therapists' singing. That is, the respondents that had the most clinical experience and the most experience with clients with Rett syndrome did not respond with the same observations.

Table 35

Relationship Between Number of Years Worked With Rett Syndrome and Relation to Therapist Singing

	Worked With Rett Syndrome Less Than 4 Years		Worked With Rett Syndrome More Than 4 Years	
Client Response to Therapist Singing	Rank	Mean	Rank	Mean
Increase Amount of Vocal/Verbal	3	1.455	1	1.000
Decrease Amount of Vocal/Verbal	4	1.600	7	5.000
Increase Vocal Pitch Range	5	2.400	4	3.000
Decrease Vocal Pitch Range	-	-	8	5.333
Increase Volume Range of Voice	6	2.500	2	2.333
Decrease Volume Range of Voice	7	3.000	5	4.000
No Noted Vocal Response	1	1.273	3	2.714
Other	2	1.143	6	4.500

Notes: A mean closer to 1.000 indicates greater agreement of respondents. The symbol (-) indicates no ranking.

There was consistency concerning the number one ranked method of choice making (see Tables 37 and 38). "Eye gaze" was chosen by each group

Table 36

Relationship of the Number of Clients With Rett Syndrome Serviced During Career and Response to Therapist Singing

	Worked With One or Two Clients		Worked With Three or More Clients	
Client Response to Therapist Singing	Rank	Mean	Rank	Mean
Increase Amount of Vocal/Verbal	1	1.250	3	1.333
Decrease Amount of Vocal/Verbal	7	4.000	5	1.750
Increase Vocal Pitch Range	3	2.333	6	3.333
Decrease Vocal Pitch Range	8	5.000	8	6.000
Increase Volume Range of Voice	5	2.800	4	1.667
Decrease Volume Range of Voice	6	3.667	7	4.000
No Noted Vocal Response	2	2.077	2	1.200
Other	4	2.600	1	1.000

Note: A mean closer to 1.000 indicates greater agreement of respondents.

(i.e., less than 4, more than 4, one or two clients, and three or more clients) with a mean ranging from 1.300 to 1.167. Three of the four groups were also

Table 37

Relationship of Number of Years Worked With Rett Syndrome and Methods of Choice Making

	Worked With Rett Syndrome Less Than 4 Years		Worked With Rett Syndrome More Than Four Years	
Client Response to Methods of Choice Making	Rank	Mean	Rank	Mean
Eye Gaze	1	1.263	1	1.231
Touching	3	1.765	2	1.833
Switch	5	2.833	4	3.000
MIDI Electronic Devices	2	1.500	5	4.000
Other	4	2.500	3	2.750
Never Experienced These Methods	-	-	-	-
No Opinion	-	-	-	-

Notes: A mean closer to 1.000 indicates greater agreement of respondents. The symbol (-) indicates no ranking.

in agreement concerning the second ranked item which was "touching". Those with less than 4 years experience ranked touching number three and "MIDI electronic devices" number two. Being that these clinicians are newer to the field, they may have had more recent computer experience than those working 4 years or more. The "other" response was ranked three, four, or five by the

Table 38

Relationship of Number of Clients With Rett Syndrome Worked With During Career and Methods of Choice Making

	Worked With One or Two Clients		Worked With Three or More Clients	
Client Response to Methods of Choice Making	Rank	Mean	Rank	Mean
Eye Gaze	1	1.300	1	1.167
Touching	2	1.684	2	2.000
Switch	4	2.833	4	3.000
MIDI Electronic Devices	3	2.000	5	3.000
Other	5	3.333	3	2.000
Never Experienced These Methods	-	-	-	-
No Opinion	-	-	-	-

Note: A mean closer to 1.000 indicates greater agreement of respondents. The symbol (-) indicates no ranking.

four groups. Responses in addition to items listed on the questionnaire included: (a) eye blinks, (b) Speak Easy and Intro Talker, (c) head nods, (d) facial expressions, (e) touching photos, (f) simple talk back tape machines, and (g) making sounds. All participants who responded had experience with these methods or had opinions concerning this topic.

Seventy-five percent of all the respondents reported that they used adaptive equipment or procedures sometimes to frequently (see Tables 39 and 40). Gentle restraining of one hand was ranked number one by three of the four groups as the procedure most frequently used with the mean ranging from 1.167 to 1.200. The participants who had less than 4 years experience ranked elbow splints number one with gentle restraining second. Elbow splints were

Table 39

Relationship of Number of Years Working With Rett Syndrome and Adaptive Equipment/Procedures Used to Encourage Independent Hand Usage

	Worked With Rett Syndrome Less Than 4 Years		Worked With Rett Syndrome More Than 4 Years	
Client Response to Adaptive Equipment/ Procedures Used	Rank	Mean	Rank	Mean
Elbow Splints	1	1.000	3	1.800
Hand Mitts	3	1.500	2	1.667
Gentle Restraining of One Hand	2	1.176	1	1.182
Do Not Use	4	1.667	4	2.000
Other	5	1.750	4	2.000

Note: A mean closer to 1.000 indicates greater agreement of respondents.

Table 40

Relationship Between Number of Clients With Rett Syndrome Worked With During Career and Adaptive Equipment Used

	Worked With One to Two Clients		Worked With Three or More Clients	
Client Response to Adaptive Equipment	Rank	Mean	Rank	Mean
Elbow Splints	2	1.250	2	1.750
Hand Mitts	3	1.500	5	2.000
Restrain One Hand	1	1.167	1	1.200
Do Not Use	4	1.667	3	1.833
Other	5	1.750	4	2.000

Note: A mean closer to 1.000 indicates a greater agreement of respondents.

ranked second by both those with one to two or three or more clients and ranked third by those with 4 or more years.

Two variations of music that music therapists have observed their clients with Rett syndrome responding most positively to was very rhythmic and fluid music (see Tables 41 and 42). Those that have 4 years or more experience and have worked with three or more girls, ranked fluid number one and very rhythmic number two. Participants with less than 4 years experience and having worked with one or two girls, ranked very rhythmic as number one and fluid as

Table 41

Relationship of Number of Years Working With Rett Syndrome and Positive Response to Music

	Worked With Rett Syndrome Less Than 4 Years		Worked With Rett Syndrome More Than 4 Years	
Client Positive Response to Music	Rank	Mean	Rank	Mean
Very Rhythmic Music	1	1.739	2	1.615
Fluid Music	2	2.190	1	1.538
Loud Music	6	2.682	6	2.538
Soft Music	3	2.227	5	2.154
Fast music	4	2.318	4	2.077
Slow Music	5	2.429	3	1.846

Notes: A mean closer to 1.000 indicates a greater agreement of respondents.

number two. Perhaps those with more experience are working with females who are older or in a later stage of the syndrome. All four of the groups placed loud music at the lowest ranking, implying that this dynamic is the least favorable for most of their clients.

Discussion

This study attempted to learn whether any demographic and/or clinical

Table 42

Relationship of Number of Clients With Rett Syndrome Worked With During Career and Positive Response to Music

	Worked With One or Two Clients		Worked With Three or More Clients	
Client Positive Response to Music	Rank	Mean	Rank	Mean
Very Rhythmic Music	1	1.609	2	1.846
Fluid Music	2	2.045	1	1.750
Loud Music	6	2.435	6	3.000
Soft Music	4	2.136	4	2.308
Fast Music	3	2.130	5	2.417
Slow Music	5	2.364	3	1.917

Notes: A mean closer to 1.000 indicates a greater agreement of respondents.

trends exist among music therapists working with females with Rett syndrome. The majority of music therapists surveyed had been clinically active for 8 or more years and had worked with females with Rett syndrome for 3 years or less. Most of the respondents had worked with two girls during their career and were presently conducting music therapy sessions with at least one client with Rett syndrome. From this data it appears that the Rett syndrome population is still relatively unknown to music therapists practicing in the United

States.

There was a preference for working alone with these clients during music therapy sessions. Forty percent of the respondents indicated individual music therapy sessions while only 16.7% held group sessions. When asked which format was more beneficial for the clients 61.1% believed it was the individual session. This response was even reported from some participants who were conducting groups. This implies that group sessions may be mandated by certain facilities, but if given a choice, the music therapist would choose individual sessions for females with Rett syndrome.

It appears that the majority of music therapists (75%) work alone during sessions. Twenty-two percent also work with related therapies (e.g., OT, PT, ST) and two respondents stated that teachers and aids participated during sessions. Sixty-one percent held sessions in self-contained classrooms but only one therapist worked in a full inclusion situation. Respondents also reported conducting sessions in day clinics and three music therapists were consultants for the school districts. These percentages may change as the trend toward full inclusion continues.

Although many participants stated they kept involved with current issues concerning Rett syndrome through parent contact, one fourth reported that they were not involved with current issues. This may be due to a lack of knowledge about where to locate information or time constraints of the job. Other means of staying informed included reviewing literature, and

maintaining contact with other school personnel or group home staff. Research is also being pursued as one respondent had recently completed her thesis on music therapy intervention and stereotypic hand patterns and another participant was implementing research that was investigating techniques to promote hand usage.

There were similarities in the goals/objectives addressed during sessions. Because loss of purposeful hand usage is one of the main criteria for the diagnosis of Rett syndrome (Rett Syndrome Diagnostic Criteria Work Group, 1988) it seemed logical that this was the most frequent goal/objective chosen by 33.3% of the respondents. With the exception of "muscle coordination" all of the goals/objectives listed were selected, at least by 1 respondent, as the most important. Because of this, and that only 8.3% ($\underline{n}$=3) chose the "other" category as their first choice, all eight music therapy goals/objectives appear to be appropriate for this population. The "other" category included goals/objectives such as: relaxation, communication, self-expression, pleasure, motivation, emotional responses, specific fine motor, and sensory integration. These findings concurred with, and expanded upon, those mentioned by Coleman & Hadsell (1988) and Coleman (1989). The goals/objectives were primarily addressed in an educational setting but could be incorporated in play therapy and at home with a tutor.

Responses about the structure of the music therapy session leaned strongly toward a set routine with improvisation for both individuals (80.6%,

n=29) and groups (58.3%, n=21). Sixty-one percent stated that individual was more beneficial than group. One respondent stated that individual sessions were preferred but felt that the clients learned a great deal through peer modeling. Rett (as cited in Lauzon) supports the importance of the individual session and also states that the addition of people to the session is acceptable but only if they are familiar.

Some trends were evident in the vocal response of clients with Rett syndrome. The primary response of the clients was vocalization (55.6%) or no vocal response other than crying or laughing (52.8%). Lindberg (1991) believes that "speech as a form of communication is not possible for these girls" (p. 125). Lindberg, as well as Montague (1990), feel that vocalizations may encourage dialogue for interaction. Although it would be beneficial for these females to develop greater interactional skills, a more important focus may be teaching these females to vocalize, rather than relying on eye gaze, in order to gain attention (Lindberg,1991).

Regarding the value of the therapist singing, the most frequent response observed by the participants was an "increase in the amount of vocalizations/ verbalizations" (41.7%) with "no noted vocal response" (36.1%) ranked a close second. This may be due to the age, stage, mood of the client, or musical selection. The majority of music therapists stated that their clients with Rett syndrome respond to tasks better when the instructions are sung rather than spoken (44%). Only four participants disagreed and no one strongly

disagreed. One respondent believed that the rhythmic cues were more critical than whether the cue was sung or not. This statement may be connected to the high response rate that "very rhythmic music" received. This warrants further investigation as this may imply that music therapy sessions need to take on a more "rhythmic" influence when addressing goals. It has been found that musical stimuli influences how the brain is prepared to receive information, it promotes behavior that pursues new experiences, and may lead to increased emotional affect (Thaut, 1990). This appears to be true of females with Rett syndrome.

When vocalizations or body language indicate that a client is upset the most beneficial intervention reported by music therapists was music. Sansom, Krishnan, Corbett and Kerr (1993) found that music therapy was an effective intervention in preventing hyperventilation and distress and Lauzon found striking tuning forks to have a calming effect on his client with Rett syndrome. Participants in this study found the following beneficial in promoting a reassuring environment: (a) keep going with the activity, (b) withdraw all stimuli and wait to start again, (c) verbal processing, (d) following close mirroring of behavior while singing a familiar song, (e) go for a walk, (f) tension and resolution with rhythm and harmony, and (g) readjust positioning. Although there are a variety of different interventions possible, music appears to the forerunner among the participants in this study. When using music as an intervention for promoting a reassuring environment, the most specific beneficial

intervention reported was singing a favorite song with accompaniment. This is smiliar to the strategy of holding, singing, and playing slow music (to reduce anxiety) mentioned by Sansom, Krisnan, Corbett and Kerr (1993). Other specific interventions that were reported effective by music therapists included singing a song with patchen and rhythmic wheelchair rocking accompanied by low pitched tone bars while singing repetitive lyrics.

There appeared to be a general agreement regarding the reaction of females with Rett syndrome to a favorite song/activity. Sixty-seven percent of the participants reported that the most typical response was a change in facial affect with the second being the movement of leaning forward. The third most typical response chosen was the "other" category which included: (a) relaxation of all muscles, (b) reaching out to touch therapists' face or instrument, (c) staring or gazing away from the source and, (d) listening intently with eye contact. This coincides with the findings of Coleman (1989) and Woodyatt and Ozanne (1992) who reported that the recognition of favorite songs by females with Rett syndrome was seen through smiling, increased levels of activity, and hyperventilation.

The reaction time of females with Rett syndrome is usually prolonged because they process one stimulus at a time (Lindberg, 1991). Participants reported that the most observed response delay was 10-30 seconds during individual sessions. The second ranked time was from 30 seconds to 1 minute. It is important to be aware of this delay because many times responses go

unnoticed. Those respondents having group sessions reported waiting 15-30 seconds to 2 minutes. A few of the respondents stated that response delay depended on the mood of the client which could vary from session to session or from minute to minute.

Some common strategies toward encouraging hand usage were observed. Thirty-three percent of the respondents used grasping instruments as a means to encourage independent hand usage. Tapping/hitting various instruments and touch requesting were closely ranked second and third. Just as Budash (1989) found the xylophone and tambourine motivating to her client to reach out, Rett (as cited in Lauzon) suggested the use of the cymbal or the gong to encourage hand use. To enable the client with Rett syndrome to use her hands purposefully, 69.9% of the participants gently restrained one hand while encouraging their client to work with the other. Some respondents never used any type of adaptive equipment or restraints for fear the hand stereotypies would only worsen when they were removed. Researchers, such as Robbins and Robbins (1994), have noted frustration in relation to the use of splints. They described a young lady who only became more agitated when her arms were kept in splints to prevent her from injuring herself. According to some of the respondents however, if adaptive equipment/procedures are used with caution and only when necessary they can temporarily improve purposeful hand usage. Twenty-five percent of the respondents reported using adaptive equipment/procedures frequently. Other methods used by participants

included: (a) velcro straps to encourage holding instruments, (b) massaging hands with lotion for relaxation, and (c) supporting one or both elbows. This is an area that needs further exploration.

Hanks (1986) feels that the use of musical instruments increases awareness and responsiveness and encourages females with Rett syndrome to physically reach out. It appears that music therapists are using a variety of instruments to encourage the whole hand cylindrical and tri-pod pincer grasp. Although there were no discernible trends, the most effective instrument chosen for the whole hand cylindrical was the tambourine followed by the egg shakers (small enough to fit snugly in the palm of the hand). Other instruments listed included: (a) rhythm sticks, (b) claves, (c) basket cylindrical shaker, (d) seed afuche, (e) African fur shaker, (f) bamboo pod shaker, and (g) shell gourd. One respondent mentioned that perhaps an area to address in a future study would be instruments used in achieving an open hand position. Many participants reported that they did not address pincer grasp because their clients were not at this level of functioning. Of those who did respond, the use of the guitar or dulcimer (plucking strings) appeared to be most effective. Items other than instruments were mentioned and included scarves and pom poms.

Trends were seen in the musical behavior of clients with Rett syndrome. A strong preference for playing a musical instrument was observed in 77.8% of the clients. When asked to rank the top three instruments the guitar, chime tree, and the omnichord were the most frequent choices of the respondents.

Although these were selected as the top three, many other instruments were closely ranked. Other instruments reported by the respondents included: (a) energy chime, (b) triangle, (c) xylophone, (d) Koudouina (Greek Bells) and (e) the sticks. Specific drums that were mentioned were the Rondondo (25" hand drum), the 14" floor tom, dubek, and lollipop handled Remo drum and the ocean drum. This finding emphasizes the need for clinicians to recognize the wide range of individual preferences of females with Rett syndrome. The response to this question may have been influenced by the instruments available to the client during the music therapy session.

The clients of the participants also showed preferences in relation to styles and tempos of music. Forty-two percent of the respondents reported a demonstrated preference for children's music. Although the ages of the females with Rett syndrome referred to in this research were unknown, it is probable that the clients were children. In addition to those eight options listed on the questionnaire, there were a variety of styles/preferences of music mentioned by the respondents. They included: (a) classical, (b) marches, (c) improvised and self composed, (d) rap, (e) drone on the guitar and low pitch fore relaxation, (f) music in upper register of piano, (g) dissonances, (h) blues themes, (i) pentatonic, (j) music from the 50's, (k) folk music, (l) pop, (m) modal, (n) Middle Eastern, and (o) Spanish. Again, this is strong statement of the individuality of females with Rett syndrome.

Fifty-six percent of the participants strongly agreed that they have

observed their clients with Rett syndrome responding positively to very rhythmic music. This may explain the preference for children's music, since it is usually quite rhythmic. It is also interesting to note, however, that reggae music, which is also has a very rhythmic influence was not selected. This may be due to lack of client exposure to this style of music or perhaps because the rhythms are often more varied than children's music or marching music. Fluid music was ranked second by 30.6% of the respondents. Soft music was preferred over loud music and fast music was ranked over slow music. Lindberg (1991) states that girls with Rett syndrome become agitated when the environment is too noisy or when "listening to blaring complex music without an easy-found rhythm or melody" (p. 27). Respondents also reported that preference depended on the client's mood during the music therapy session. The stage of the syndrome may also influence the female's preference. When respondents were compared as to the number of years they had worked with Rett syndrome and the number of clients with Rett syndrome serviced, those that had more than 4 years experience and worked with more than 3 females ranked fluid music first and rhythmic music second. These rankings were reversed for those who had less than 4 years working and only one or two clients.

When asked to determine the percentage of live and recorded music they used during sessions, the majority of respondents used live music with 41.7% using it 100% of the time. When using live music the most preferred instrument of music therapists was the voice. Recorded music was used an

average of 24.381% by participants. Perhaps the reason that live and vocal music appears to be preferred is that they allow for more interaction to take place as they both are extremely versatile and therapist is in control of and can respond to what the client is expressing. This is the basis of improvisational music therapy which Robbins and Robbins (1994) have found very effective.

There were also trends apparent in communication. Forty-seven percent of the respondents most frequently offered instrument choices to their clients with Rett syndrome. Although there is no documentation concerning choice making, instruments have been used to motivate clients with Rett syndrome to reach out and manipulate (Hanks, 1986; Coleman, 1987). Another trend in communication was seen in the use of eye gazing to make choices. This was ranked number one by all four groups consisting of those with less than 4 years clinical experience, those with more than 4 years experience, those who worked with one or two clients with Rett syndrome, and those who worked with three or more.

This results of this study indicate that there are general trends of techniques used, similarities of goals and objectives addressed, similar tendencies of vocal and non-vocal response to music intervention, common strategies toward encouraging hand usage and a preferred choice of instruments and adaptive equipment used.

The survey was meant to generate ideas and provide a starting point for other research. Each question could become the basis of a complete research

project. This survey was also meant to provide information for those music therapists who have limited experience with clients with Rett syndrome and desire further information in regarding appropriate treatment procedures. In addition, for parents of these clients, this research may be helpful in gaining access to music therapy services within the school system.

Recommendation for Future Study

Because this survey was possibly the first attempt to collect information regarding music therapy and Rett syndrome, further research in this area is needed. This research provides only a basis of general information about the combination of these two areas.

Five specific areas that need further exploration in relation to music therapy are purposeful vocalization, rhythmic music, adaptive equipment/ procedures, the four stages of Rett syndrome and family interaction. Levels of vocal response differ from individual to individual in these clients. From the results of the present study, it appears that many females increase the amount of vocalizations when the therapists sings to them, yet almost the same amount demonstrate no noted vocal response. Many questions remain unanswered. Is this difference related to the age and stage of the client or perhaps to the intellectual functioning level? Does vocalizing depend on the music the therapist is presenting?

Many of the females with Rett syndrome responded positively to

rhythmic music. Further research may determine how rhythm is best incorporated in the music therapy session. Perhaps speaking the directions rhythmically or focusing more on using the clients' hand patterns in the music may affect how the clients respond. Do some rhythms stimulate more than others? Does the instrumentation used to perform the rhythms stimulate clients differently ?

The use of adaptive equipment/ procedures to encourage independent hand usage warrants further inquiry, Specifically, music therapists would benefit from learning how splints are used in the clients every day life, how the use of splints influences its effectiveness during music therapy, whether music therapists should restrain from using these methods and use music exclusively as a motivator, or if adaptive equipment/procedures should be used regularly by music therapists? Having a clearer understanding of these questions would be very beneficial for improved progress and comfort of the individual with Rett syndrome.

It is recommended that research be conducted investigating the role of music therapy and the four stages of Rett syndrome. Each stage brings change which evokes emotions and loss of skills. As they adapt to these changes, the girls/women with Rett syndrome may respond to musical stimuli differently or require new musical interventions to meet their needs. Research to determine the most productive use of music at specific stages will surely benefit the client.

It is always important to focus on the person with Rett syndrome as a

whole, including her family. The ultimate goal of music therapy is generalization of skills and behavior to other areas of life. More information is needed in order to determine how and what music is used in the clients' homes. Are the caregivers aware of what goes on during music therapy sessions? Are they carrying over the use of music in the home?

Another beneficial area of research would regard the physical positioning of clients during music therapy. Does the physical positioning (i.e., sitting, standing, lying down) effect client response? Are there preferred ways of supporting or restraining the arm for improved movement? Research conducted in conjunction with a physical therapist would provide helpful information.

Because of the small percentage of females with Rett syndrome it is difficult to conduct experimental research. A feasible approach to this type of research may be field experimentation. This would involve designing a specific research method and asking music therapists working with females with Rett syndrome, to implement it and report their findings. The results would be videotaped and sent back to the researcher.

Continued research will strongly impact the success of future music therapy sessions and may provide important information to further define the behaviors and characteristics of Rett syndrome.

Appendix A

Diagnostic Criteria and Permission to Use Tables

Necessary Criteria[a]
Apparently normal prenatal and perinatal period
Apparently normal psychomotor development through the first 6 months[b]
Normal head circumference at birth
Deceleration of head growth between ages 5 months and 4 years
Loss of acquired purposeful hand skills between ages 6 and 30 months, temporally associated with communication dysfunction and social withdrawal
Development of severely impaired expressive and receptive language, and presence of apparent severe psychomotor retardation
Stereotypic hand movements such as hand wringing/squeezing, clapping/tapping, mouthing and "washing"/rubbing automatisms appearing after purposeful hand skills are lost
Appearance of gait apraxia and truncal apraxia/ataxia between ages 1 and 4 years
Diagnosis tentative until 2 to 5 years of age

Supportive Criteria
Breathing dysfunction
  Periodic apnea during wakefulness
  Intermittent hyperventilation
  Breath-holding spells
  Forced expulsion of air or saliva
EEG abnormalities
  Slow waking background and intermittent rhythmical slowing (3–5 Hz)
  Epileptiform discharges, with or without clinical seizures
Seizures
Spasticity, often with associated development of muscle wasting and dystonia
Peripheral vasomotor disturbances
Scoliosis
Growth retardation
Hypotrophic small feet

Exclusion Criteria[a]
Evidence of intrauterine growth retardation
Organomegaly or other signs of storage disease
Retinopathy or optic atrophy
Microcephaly at birth
Evidence of perinatally acquired brain damage
Existence of identifiable metabolic or other progressive neurological disorder
Acquired neurological disorders resulting from severe infections or head trauma

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[a]Modified from Hagberg et al [8].
[b]Development may appear to be normal for up to 18 months.

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WESTERN MICHIGAN UNIVERSITY

August 9, 1995

This signifies that Stacy S. Gay may reproduce the tables entitled "Rett Syndrome: Clinical Characteristics and Differential Diagnosis by Stage" and "Diagnostic Criteria for Rett Syndrome". These are taken from the "Diagnostic Criteria for Rett Syndrome" article in the April 1988 Annals of Neurology.

The tables will be used in her Master's thesis titled "Music Therapy and Rett Syndrome: A Survey of Music Therapy Practitioners".

8/15/95
Date

Kathy Hunter
Kathy Hunter, President
International Rett Syndrome Assoc.

Appendix B

Stages of Rett Syndrome

Table 2. Rett Syndrome: Clinical Characteristics and Differential Diagnosis by State

States (after Hagberg and Witt-Engerstrom [10])	Clinical Characteristics	Differential Diagnosis
Early onset deceleration stage Onset: 6–18 months Duration: months	Developmental stagnation Deceleration of head/brain growth Disinterest in play activity Hypotonia	Benign congenital hypotonia Prader-Willi syndrome Cerebral palsy
Rapid "destructive" stage Onset: 1–3 years Duration: weeks to months	Rapid developmental regression with irritability Loss of hand use Seizures Hand stereotypies: wringing, clapping/tapping, mouthing Autistic manifestations Loss of expressive language Insomnia Self-abusive behavior (e.g., chewing fingers, slapping face)	Autism [13–15] Psychosis Hearing or visual disturbance Encephalitis Infantile spasms (West syndrome) [16] Tuberous sclerosis Ornithine transcarbamylase deficiency [17] Phenylketonuria Infantile neuronal ceroidlipofuscinosis
Pseudostationary stage Onset: 2–10 years Duration: months to years	Severe mental retardation/apparent dementia Amelioration of autistic features Seizures Typical hand stereotypies: wringing, tapping, mouthing Prominent ataxia and apraxia Spasticity Hyperventilation, breath holding, aerophagia Apnea during wakefulness Weight loss with excellent appetite Early scoliosis Bruxism	Spastic ataxic cerebral palsy Spinocerebellar degeneration Leukodystrophies or other storage disorders Neuroaxonal dystrophy Lennox-Gastaut syndrome Angelman syndrome [18]
Late motor deterioration stage Onset: 10 + years Duration: years	Combined upper and lower motor neuron signs Progressive scoliosis, muscle wasting, and rigidity Decreasing mobility—wheelchair-bound Growth retardation [12] Improved eye contact Staring, "unfathomable" gaze Virtual absence of expressive and receptive language Trophic disturbance of feet Reduced seizure frequency	Unknown degenerative disorder

Appendix C

Demographic Survey and Cover Letter

Demographic Information

1. Name _____

2. Please circle all credentials applicable to you.
    a. Bachelor
        1. Music Therapy
        2. Music Education
        3. Equivalency Degree in Music Therapy
        4. Other _____
    c. Master
        1. Music Therapy
        2. Music Education
        3. Other _____
    d. Doctorate
        1. Music Therapy/Education
        2. Other _____
    e. RMT
    f. CMT
    g. Board Certified

3. How long have you been practicing as a music therapist?
    a. Less than 1 year
    b. 1 - 3 years
    c. 3 - 8 years
    d. 8 + years

4. How long have you been working with girls with Rett syndrome?
    a. 0 - 2 months
    b. 3 months - 1 year
    c. 1 - 2 years
    d. 2 - 3 years
    e. 3 - 4 years
    f. 4 - 6 years
    g. 6 - 8 years
    h. 8 +

5. As a music therapist, how many girls with Rett syndrome have you worked with?
    a. 1
    b. 2
    c. 3
    d. 4
    e. 5
    f. 6 - 8
    g. 8 - 10
    h. 10-12
    i. 12 +

6. How many girls with Rett syndrome are you presently working with?
    a. 1
    b. 2
    c. 3
    d. 4
    e. 5
    f. 6 - 8
    g. 8 - 10
    h. 10 - 12
    i. 12 +

7. How many times per week do you work with the girl(s)?
   a. 1
   b. 2
   c. 3
   d. 4
   e. 5
   f. 6 +

8. How long do your sessions last?
   a. 15-25 minutes
   b. 30 minutes
   c. 45 minutes
   d. 1 hour
   e. 1 hour and 15 minutes +

9. How are your music therapy sessions scheduled?
   a. Individual
   b. Group
   c. Both

10. During your sessions, do you work alone or directly with other therapists (i.e. physical, occupational, etc.)?
   a. Alone
   b. With other therapists

11. In what setting do you provide music therapy sessions? Please circle all that apply.
   a. Self-contained classroom
   b. Mainstreamed situation
   c. Full inclusion situation
   d. Individual pull-out program in school setting
   e. Private practice
   f. Other _____

12. In what ways are you involved with current issues concerning Rett syndrome?
   a. Not involved
   b. Parent contact
   c. Member of International Rett Syndrome Association (IRSA)
   d. Attend IRSA conferences
   e. Attend local Rett syndrome parent groups
   f. Other _____

13. Overall, what music therapy interventions do you feel are most effective with girls with Rett Syndrome?

_____

_____

_____

14. Do you know of any other music therapists that are working with girls with Rett syndrome?

Name _____ Name _____
Address _____ Address _____
_____ _____
_____ _____

College of Fine Arts
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WESTERN MICHIGAN UNIVERSITY

February 6, 1995

Dear Fellow Music Therapist:

As awareness of Rett syndrome increases, the emphasis on the importance of music therapy intervention has become more prominent. Based on the recommendation of Dr. Rett, many parents are now insisting that music therapy be included in their daughters' Individual Education Programs. This has lead to an increased demand for music therapists within special education programs.

As part of my graduate study coursework at Western Michigan University, I am interested in examining how effective music therapy is in the treatment of girls with Rett syndrome. The enclosed survey is designed to provide demographic information that will assist me in designing a formal survey for my thesis research. It will only take a few minutes of your time to complete. Please return the survey on or before February 23, 1995, in the stamped envelope provided.

If you have any questions or comments please feel free to contact me at (616) 387-4679. Thank you for your time and willingness to assist me.

Sincerely,

Stacy Gay, RMT-BC
School of Music
Western Michigan University
Kalamazoo, MI 49008-3831

Appendix D

Questionnaire and Cover Letter

Questionnaire

Name _____

Goals and Objectives

1. Please arrange in order of importance (1= most important) goals/objectives that you typically address during your session.

____a. Hand usage	____e. Attention span
____b. Vocal response	____f. Eye contact
____c. Cause and effect	____g. Choice making
____d. Muscle coordination	____h. Other_____

2. Are any of these goals/objectives addressed in other areas of the girls'/women's every day living?
____ Yes
____ No

If Yes, please circle all that apply.
a. In related therapies (PT, OT, ST)
b. At home by caregiver
c. In educational setting
d. Other_____

Session Structure

3. My **individual** sessions are structured in the following manner:
(please circle one)
a. Set routine w/out improvisation
b. Set routine with improvisation
c. Complete improvisation

4. My **group** sessions are structured in the following manner:
(please circle one)
a. Set routine w/out improvisation
b. Set routine with improvisation
c. Complete improvisation

5. Overall, do you feel that individual or group music therapy sessions are more beneficial for girls/women with Rett syndrome?
a. Individual more beneficial
b. Group more beneficial
c. Equally beneficial
d. No opinion

Vocal Response

6. What is the verbal and/or vocal response of the girls/women you have worked with? Please circle all that apply.
a. Intelligible verbalization
b. Primarily vocalization with some intelligible verbalization
c. Vocalization
d. No vocal response other than crying or laughing
e. No opinion

7. In general, how do the girls/women respond to your singing during music therapy sessions? (please arrange in order, 1= most frequent response)

___a. Increase amount of vocalizations/verbalizations	____e. Increase volume range of voice
___b. Decrease amount of vocalizations/verbalizations	____f. Decrease volume range of voice
___c. Increase vocal pitch range	____g. No noted vocal response
___d. Decrease vocal pitch range	____h. Other_____

8. The girls/women respond better to tasks when the instructions are sung rather than spoken.

Strongly agree Unsure Strongly Disagree
1 2 3 4 5

9. When the girls/women appear to be upset, what interventions have you found beneficial in promoting a reassuring environment? Please arrange in order (1= most beneficial).

___a. Hold/physical touch
___b. Refrain from touching first, letting her make interaction
___c. Introduce new activity
___d. Preferred or familiar activity
___e. Music intervention
___f. Other_____
___g. I have not had this experience

10. If you use music to promote a reassuring environment, what specific interventions do you use? Please arrange in order (1= most effective).

___a. Sing favorite song a cappella
___b. Sing favorite song with accompaniment
___c. Sing song specific to the situation a cappella
___d. Sing song specific to the situation with accompaniment
___e. Improvise instrumental music specific to situation
___f. Improvise vocal music specific to the stituation
___g. Listen to recorded music
___h. Other_____

Non-Verbal Response

11. In recognition of a favorite song/activity the girls/women usually respond by: (please arrange in order, 1= most typical response)

___a. Hyperventilating
___b. Laughing
___c. Leaning forward
___d. Increasing hand stereotypies
___e. Changing facial affect
___f. Vocalizing
___g. Other_____

12. When waiting for a reaction from the girls/women, what is the average response delay that you have observed?

a. 5 -10 seconds
b. 10 -30 seconds
c. 30 seconds to 1 minute
d. 1 to 2 minutes
e. 2 to 4 minutes
f. 4 or more minutes
g. Due to my group sessions, I am limited to waiting _____(minutes, seconds)

Hand Usage

If you do not address hand usage as a goal/objective please go to question 17.

13. In what ways do you encourage hand usage during your sessions? Please arrange in order (1=most frequently used).

___a. Grasping instruments
___b. Switch activating
___c. Touch requesting
___d. Strumming various instruments
___e. Tapping, hitting various instruments
___f. Using sign language
___g. Other_____

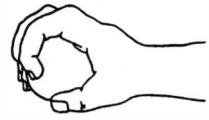
14. Which of the following adaptive equipment or procedures do you use during your music therapy sessions to encourage independent hand usage? Please arrange in order (1= most frequently used).

___a. Elbow splints
___b. Hand mitts
___c. Gentle restraining of one hand
___d. Do not use
___e. Other

15. How often do you use the above mentioned adaptive equipment/procedures during your sessions?

Frequently Sometimes Never
1 2 3 4 5

16. What instruments do you find most effective in encouraging hand usage? Please arrange in order.
Whole hand cylindrical (1= most effective)



___a. Maraca
___b. Mallet for tone block, drum, etc.
___c. Cabasa
___d. Tambourine
___e. Jingle Bells
___f. Other_____

Pincer (1= most effective)

___a. Melodee bells
___b. Finger chimes
___c. Guitar, dulcimer, etc. (plucking strings)
___d. Other _____

Musical Behavior

17. Do the girls/women display a preference for playing a favorite instrument?
___a. Yes
___b. No

If you answered yes, please rank the top three instruments of choice (1= most preferred)

___a. Tambourine
___b. Drum, specifically the _____
___c. Cabasa
___d. Tone block
___e. Cymbal
___f. Omnichord
___g. Autoharp
___h. Chime tree
___i. Bells
___j. Maracas
___k. Guitar
___l. Piano
___m. Electronic keyboard
___n. Other_____

18. What percentage of time do you use live and recorded music in a session? (0%-100%)
a. Live music _____
b. Recorded music _____

19. If you use live music in your work, what 3 instruments do you use most frequently? Please arrange in order (1=most preferred)

___a. Piano
___b. Keyboard
___c. Guitar
___d. Omnichord
___e. Voice
___f. Other_____
___g. Do not use

20. What musical styles/preference have your client(s) displayed? Please arrange the top 3 in order (1= most preferred).

___a. Rock
___b. Easy listening
___c. Jazz
___d. Country
___e. Reggae
___f. Children's music
___g. Church
___h. Other_____
___i. No opinion

21. In my opinion my clients with Rett syndrome positively respond to: (Please circle appropriate number)

	Strongly Agree		Unsure		Strongly Disagree
a. Very rhythmic music	1	2	3	4	5
b. Fluid music	1	2	3	4	5
c. Loud music	1	2	3	4	5
d. Soft music	1	2	3	4	5
e. Fast music	1	2	3	4	5
f. Slow music	1	2	3	4	5

Adaptive Communication

22. What choices do you offer the girls/women? Please arrange in order (1= most frequently offered).
___a. Song choices
___b. Instrument choices
___c. Activity choices
___d. Choice to repeat activities
___e. Other _____

23. What methods have you found to be effective in encouraging choice making?
Please arrange in order (1= most effective).
___a. Eye gaze
___b. Touching
___c. Switch
___d. MIDI electronic devices
___e. Other_____
___f. I have never experienced these methods
___g. No opinion

24. If you use a switch with your girls/women, what type and brand do you use?
a. Type _____
Brand _____
b. I do not use a switch

25. What other adaptive communication devices have you found useful in working with this population? Please describe briefly.
a. _____
b. _____
c. _____
d. I do not use adaptive equipment

26. What specific resources (e.g. books, songs, activities, recordings) would you recommend to other music therapists working with girls/women with Rett syndrome?

_____
_____
_____
_____

College of Fine Arts
School of Music
Music Therapy Clinic

Kalamazoo, Michigan 49008-3831
616 387-4679

WESTERN MICHIGAN UNIVERSITY

April 21, 1995

Dear Fellow Music Therapist:

Sometime ago I sent a demographic survey to music therapists known to work with girls/women with Rett syndrome. Based on the information I received, the enclosed questionnaire was devised to determine general goals, observed client responses and music therapy interventions being used with this population.

Participation in the study is completely voluntary, and the return of your completed questionnaire constitutes your informed consent to act as a subject in this research. Names will not be released in the publication of any data. Surveys will be kept in a locked file cabinet in my office and will be destroyed after the data have been transferred to a computer data file. Please take a few minutes to complete and return the questionnaire on or before **May 12, 1995** in the stamped envelope provided.

To encourage continuation of idea sharing, I would like to create a directory of participants in this study that would be made available to clinicians who work with girls/women with Rett syndrome. The directory would consist of the name, credentials, address and work telephone number of those interested respondents. If you would like to be included in this directory and receive a copy of the results, please contact me at: School of Music, Western Michigan University, Kalamazoo, MI 49008-3831, 616-387-6430.

Thank you in advance for your participation.

Sincerely,

Stacy Gay

Stacy Gay, RMT-BC
School of Music
Western Michigan University
Kalamazoo, MI 49008-3831

Appendix E

Approval Forms for Human Subjects Institutional Review Board

College of Fine Arts
School of Music
Music Therapy Clinic

Kalamazoo, Michigan 49008-3831
616 387-4679

WESTERN MICHIGAN UNIVERSITY

March 14, 1995

Chair, HSIRB
Office of Research and Sponsored Programs
Western Michigan University
Kalamazoo MI 49008

To whom it may concern:

This is to confirm that I have reviewed the research protocol submitted by Stacy Gay for her thesis project entitled, "Music Therapy and Rett Syndrome: A Survey of Music Therapy Practioners," and concur that it should be considered as exempt from full HSIRB review. (067-10-9278)

Sincerely.

Richard O'Hearn, Ph.D., Director
School of Music

Human Subjects Institutional Review Board

Kalamazoo, Michigan 49008-3899
616 387-8293

WESTERN MICHIGAN UNIVERSITY

Date: March 13, 1995

To: Gav, Stacy S.

From: Richard Wright, Interim Chair for R. Wright

Re: HSIRB Project Number 95-03-08

This letter will serve as confirmation that your research project entitled "Music therapy and Rett syndrome: A survey of music therapy practitioners" has been approved under the exempt category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you must seek specific approval for any changes in this design. You must also seek reapproval if the project extends beyond the termination date. In addition if there are any unanticipated adverse or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: Mar 13, 1996

xc: Wilson, Brian, MUS

Appendix F

Cover Letter for New Participants

April 21, 1995

Dear Fellow Music Therapist:

As awareness of Rett syndrome increases, the emphasis on the importance of music therapy intervention has become more prominent. Based on the recommendation of Dr. Rett, many parents are now insisting that music therapy be included in their daughters' Individual Education Programs. This has led to an increased demand for music therapists within special education programs.

As part of my graduate study coursework at Western Michigan University, I am interested in examining how effective music therapy is in the treatment of girls with Rett syndrome. The enclosed questionnaire is designed to provide demographic information, general goals, observed client responses and music therapy interventions being used.

Participation in the study is completely voluntary, and the return of your completed questionnaire constitutes your informed consent to act as a subject in this research. Names will not be released in the publication of any data. Surveys will be kept in a locked file cabinet in my office and will be destroyed after the data have been transferred to a computer data file. Please take a few minutes of your time to complete and return the questionnaire on or before **May 12, 1995**, in the stamped envelope provided.

To encourage continuation of idea sharing, I would like to create a directory of participants in this study that would be made available to clinicians who work with girls/women with Rett syndrome. The directory would consist of the name, credentials, address and work telephone number of those interested respondents. If you would like to be included in this directory and receive a copy of the results please contact me at: School of Music, Western Michigan University, Kalamazoo, MI 49008-3831, 616-387-4679.

Thank you in advance for your participation.

Sincerely,

Stacy Gay, RMT-BC
School of Music
Western Michigan University
Kalamazoo, MI 49008-3831

Appendix G

Follow Up Cover Letter

College of Fine Arts
School of Music
Music Therapy Clinic

Kalamazoo, Michigan 49008-3831
616 387-4679

WESTERN MICHIGAN UNIVERSITY

May 24, 1995

Dear Fellow Music Therapists:

A few weeks ago you received a questionnaire concerning Rett syndrome and music therapy. I am currently in the process of analyzing and interpreting the results of this study.

If you have not yet returned the survey, it is not too late. The survey will only take a short time to complete. Please mail the additional enclosed copy of the already received survey in the envelope provided for you before June 5. The greater the number of surveys returned the more valid the results of the study will be.

I remind you that if you would like a copy of the results of the study and to be included in the participant directory (which would include: name, credentials, address and work telephone number) please contact me at: School of Music, Western Michigan University, Kalamazoo, MI 49008-3831, 616-387-4679.

Thank you again for your time and consideration. It is greatly appreciated!

Sincerely,

Stacy Gay

Stacy Gay, RMT-BC

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