

# **A Case Study of Using Music Therapy Interventions to Enhance Quality of Life in Environmental Domain in a Person with Facioscapulohumeral Muscular Dystrophy**

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## **ABSTRACT**

This case study aimed to investigate the effectiveness of music therapy interventions on quality of life in environmental domain in a person with Facioscapulohumeral Muscular Dystrophy. The participant participated in 12 music therapy sessions (60 min/session) twice a week. The first seven sessions were individual sessions and the last five sessions were group session associated with the caregiver. Music therapy interventions included live music, singing and playing instruments, song choice, lyrics analysis, and improvisation. The WHOQOL-BREF-THAI questionnaire was utilized to the participant at the end of every two weeks to measure the participant's quality of life and the interviews with a caregiver were conducted separately. Data were presented in the qualitative case analysis, visual analysis and interview inductive analysis. The results supported that the participant's quality of life in environmental domain was enhanced. The participant's WHOQOL-BREF-THAI in environmental domain scores were increased from 19 to 28 points. Moreover, the music therapy interventions helped the bonding between the participant and the caregiver, also brought blissful atmosphere to staff.

**Keywords:** Music therapy, Facioscapulohumeral Muscular Dystrophy, Quality of life

## **1. INTRODUCTION**

Muscular Dystrophy (MD) is a group of progressive muscle disease caused by inherited genes mutations. The mutated genes affect the muscle's strength and function. Persons with MD usually suffer from physical disability (Emery, 2008; Stajich, 2003). Facioscapulohumeral Muscular Dystrophy (FSHD) is a type of MD that has effects on facial,

shoulder, and upper arm muscles (Campellone & Fetterman, 2016). With the disease progression, FSHD can also affect lower limbs' muscle function. The cure for FSHD has not yet been found but the progression of FSHD is slow, compared to Duchenne Muscular Dystrophy (Angelini, 2013; Witoonpanich, 2012). Since FSHD limits the person's mobility, environmental domain is crucial for the person's quality of life. Therapy to enhance the quality of life in persons with FSHD is highly recommended.

Quality of life (QOL) refers to multidimensional concepts, depending on individual's perspective of life's value (World Health Organization, 1997). World Health Organization (WHO) published WHOQOL-100 and WHOQOL-BREF assessments as tools to measure the impact of health from health care. In WHOQOL-BREF questionnaire, environment domain consists the facets of 1) freedom, physical safety and security, 2) home environment, 3) opportunities for acquiring new information and skills, 4) participation in and opportunities for recreation / leisure activities, 5) health and social care: accessibility and quality, 6) physical environment (pollution / noise / traffic / climate), 7) transportation and 8) financial resources (World Health Organization, 1996).

Music therapy is the evidence-based use of music elements which are carefully chosen by a credentialed music therapist to design music therapy interventions in order to address non-musical goal of individual's need through a therapeutic relationship (American Music Therapy Association, 2016). Music therapy is often used to create non-threatening environment in various health care settings (Davis, Gfeller, Thaut, 2008; King, 2004). Moreover, research studies showed that music therapy could enhance quality of life in hospice care, elderly persons, and persons with developmental disabilities (Hillard, 2002; Cho, 2016; Li, 2010) and could also provide opportunities to acquire new skill and leisure activities (Barksdale, 2003). However, there was no music therapy research on quality of life in environment domain in persons with FSHD. Hence, the gap of knowledge is needed to be fulfilled. This study aimed to investigate the effectiveness of music therapy interventions on quality of life in environmental domain in a person with FSHD. The research questions were 1) Does music therapy enhance quality of in environmental domain in a person with FSHD? and 2) How can music therapy enhance quality of life in environmental domain in a person with

FSHD? The value of this study is to develop the music therapy interventions that can be used efficiently to address the needs of a person with FSHD. The knowledge from this study should be useful for further generation of music therapists to design appropriate music therapy interventions for FSHD population.

## **2. METHODOLOGY**

The case study design was utilized to investigate the effectiveness of music therapy interventions on quality of life in environmental domain in a person with FSHD.

### ***2.1 Participant***

This study was approved by the Ethics Committee, Mahidol University. The participant was a 58-year-old Thai female who was diagnosed with FSHD. Her FSHD onset was in 9<sup>th</sup> grade, starting from her right index finger. She came from a family of four members; all of her family members had passed away. In adulthood, the participant frequently played the guitar and keyboard with her friends. She used music to relax herself from intense education. Later on, she was a Chemistry and English teacher. By the age of 44, her symptom went severe so she had to retire from her career. She then moved from her hometown to Bangkok. Due to her physical limitation, she was wheelchair bound. She had to be taken care of by her caregiver at all time. According to the caregiver, the participant mostly complained about environment domain. The participant was referred to participate in music therapy sessions by a lecturer from her university who witnessed her ability and interest in music during the university's event. The lecturer also saw the potential that she could benefit from music therapy interventions.

The participant was a 58-year-old Thai female. The participant was wheelchair bounded, currently living in a university dormitory with her caregiver.

### ***2.2 Music Therapy Interventions***

The music therapy sessions were conducted in a private room. The researcher as a music therapist was responsible for planning music therapy interventions based on the Reporting Guidelines for Music-based interventions (Robb, Burns & Carpenter, 2010) to enhance the participant's quality of life in environment domain. The music therapy

interventions were designed based on the Cognitive-behavioral Music Therapy Approach and the participant's music preferences, and were delivered live by the music therapist. It consisted of 1) music-relaxation, 2) music listening 3) singing, 4) playing music instruments 5) improvisation and 6) lyrics analysis.

### **2.3 Procedure**

There was one initial assessment before the music therapy session phase for the music therapist to build rapport, assess the participant's physical ability, gather the participant's music preferences, and collect the WHOQOL-BREF-THAI in environment domain scores; the participant was asked to complete the WHOQOL-BREF-THAI quality of life questionnaire, the total score in environment domain of the WHOQOL-BREF-THAI questionnaire is 40 points, which can be rated as 8-18 points represent low, 19-29 points represent medium, and 30-40 points represent high.

After the initial assessment, the music therapist made an arrangement with the participant for the music therapy phrase schedule and planned music therapy interventions for each session to address the goal. Music therapy phase was divided into two types: 7 individual sessions and 5 group sessions, there were 12 music therapy sessions in total. The music therapy sessions were conducted twice a week, each session lasted 60 minutes. The music therapy interventions consisted of greeting, music relaxation, singing / playing instrument/improvising and lyrics analysis, and farewell. There was video recording in every session for the music therapist to observe and write session notes.

By the end of every two weeks, the participant was asked to fill out the WHOQOL-BREF-THAI quality of life questionnaire by oneself. Also, the caregiver's interviews were conducted four times separately from the music therapy session. In order to gather the inclusive information along with the participant's WHOQOL-BREF-THAI questionnaire result, therefore, the period of the interview as same as the questionnaire, which were; the initial interview, the interview after the fourth music therapy session, the interview after the eighth music therapy session, and the interview after the twelfth music therapy session.

In evaluation phase, the information was gathered from 1) video recording observation, 2) the participant's quality of life self-reports and 3) the caregiver's interviews.

## **2.4 Data analysis**

2.4.1 *Case study data analysis* was adapted from Creswell (2007) to narrate in-depth information that occurred during the study. Hence, case study data analysis was used to analyze the qualitative result of the participant's quality of life in environment domain during the music therapy sessions from videotape.

2.4.2 *Visual inspection*, adapted from Wheeler (2005) and Kazdin (1982), was used to evaluate the effectiveness of the music therapy interventions and display in graph plotting. The data of self-report WHOQOL-BREF-THAI quality of life questionnaire was displayed in level, slope, and trend.

2.4.3 *Inductive analysis* was used to analyze the participant's behavior changes under environment domain from the caregiver's perspective.

## **3. RESULTS AND DISCUSSION**

### **3.1 Results from video recording observation**

#### *Initial Assessment*

After the referral process, I went to introduce myself to the participant and asked if she was interested to participate in music therapy sessions, which she agreed. I asked her to complete the WHOQOL-BREF-THAI questionnaire and signed the IRB approval documents. During the initial assessment, I witnessed her limitation in physical movement. She could not move her body much. She controlled her electronic wheelchair by her fingers. Choosing a room for the sessions was quite difficult due to her FSHD symptoms and previous record of pneumonia. I gathered her information and music preference to design the music therapy interventions for the first music therapy session on the next week.

#### *Treatment Process and Session Summary*

During the 1<sup>st</sup>-4<sup>th</sup> music therapy sessions, I used her music preferences as based for every music therapy interventions. During the 1<sup>st</sup> music therapy session, the participant stated that the sound of the guitar made her feel like homesick. Later on in the session, she engaged more in the music therapy activity by playing the shaker and singing, she felt the joy and reported that, music makes her feel like she was already home. The melodies of her familiar

songs combine with the sound of the guitar create a home-like environment for the participant. During the 4<sup>th</sup> session, the participant looked out the window during singing her favorite song by memory and reported that she noticed the beauty of her environment. I also introduced her to an activity called Music journey which I improvised guitar chord progressions in the key of C major and asked the participant to sing any song as she wished to. She started to sing slow song and gradually speeded up the tempo of each song she chose. She stated that the lyrics and melodies of each song made her feel like she was on a road trip with her friends. Also, she acquired new musical skills in playing the ukulele, shakers, and drums.

During the 5<sup>th</sup> – 8<sup>th</sup> music therapy sessions, I used improvisation technique to encourage the participant to look outside the window of the setting while she was singing or playing. Singing and playing without sheet music provided a wider perspective for the participant. Moreover, I used Music-relaxation to provide a tranquil and safe space for the participant to express her feelings. During the 7<sup>th</sup> session, I introduced the participant to music arrangement technique and asked her to re arrange the music such as changing tempo, rhythm, instruments and form. She also acquired new musical skills in playing the xylophone, Q-Chord, and more importantly she had an opportunity to play her favorite instrument, the keyboard, after she had not played it for many years since she was sick.

During the 9<sup>th</sup> and 12<sup>th</sup> music therapy sessions, the participant had an opportunity to experience the new style of music therapy as group. The participant and her caregiver had opportunities for leisure activity. They learned how to communicate through music, respect each other's opinion in song choice. Especially in the 11<sup>th</sup> session, the participant told me that she had an argument with staffs and her caregiver. She was depressed and downhearted. I used the sound of the cello to elevate her spirit. It was her first time to listen to the sound of the cello. She was amazed by the timbre of the instrument. She then stated that *"I'm amazed by the beauty of the sound that I've never heard in my life. It gives me hope and strength to live and explore new sounds in the world I would have missed if I had not chosen to live"*. In the last music therapy session, the participant, the caregiver and a staff that was invited by the participant to join the session turned the setting to a music stage. They had fun in singing

and playing together. The caregiver and the staff danced to the music. The participant make jokes after the song had ended that brought a blissful laughter to the session.

The table 1 showed the summary of the participant's quality of life in environment domain according to WHOQOL-BREF-THAI.

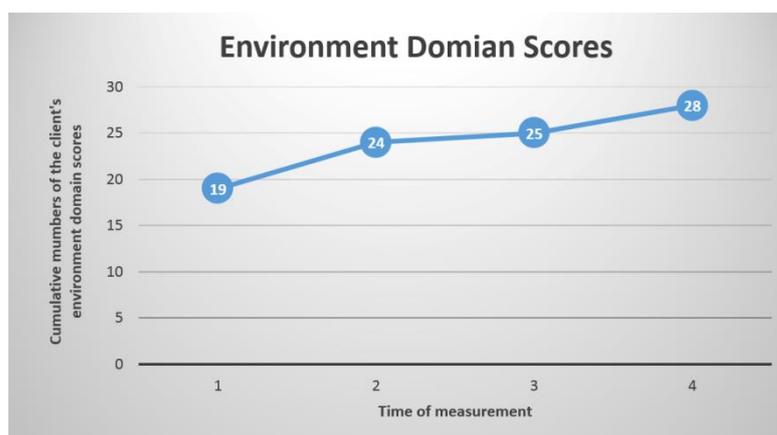
Table 1 Summary of the participant's quality of life in environment domain according to WHOQOL-BREF-THAI

Facets in environment domain	Results	Music therapy interventions
Freedom, physical safety and security	Improved	Music relaxation and improvisation provided freedom, safety, and security environment.
Home environment	Improved	Preferred music and familiar sound created home environment for the participant.
Opportunities for acquiring new information and skills	Improved	The participant acquired new musical skills: singing, breathing exercise, music theory, music arrangement, and playing instrument.
Participation in and opportunities for recreation / leisure activities	Improved	Music therapy interventions provided relax, fun, and joyful time to the participant.
Health and social care: accessibility and quality	Not improved	-
Physical environment (pollution / noise / traffic / climate)	Improved	Music harmony created blissful sound and distracted the participant from the outside's noise.
Transportation	Improved	Familiar music transported the participant's mind to desire places.
Financial resources	Not improved	-

### 3.2 Visual Analysis of Quality of Life in environment domain

The visual analysis was utilized to analyze the participant's quality of life scores in environment domain in total 4 periods of times; initial assessment, after the fourth music therapy session, after the eighth music therapy session, and after the twelfth music therapy session.

In initial assessment, the participant scored 19 points. After the fourth music therapy session, the participant scores dramatically increased from 19 to 24 points. Then, after the eighth music therapy session, the score slightly increased from 24 to 25 points. Lastly, after the twelfth music therapy session, the score reached 28 points. The line graph was presented below (Figure 1).



(Figure 1) Cumulative numbers of the client's environment domain scores

### 3.3 Interview Findings

This section presented the interview findings from the caregiver. The number behind each quote indicated the period of the interview. Number 1 indicated the initial interview, number 2 indicated the interview after the fourth music therapy session, number 3 indicated the interview after the eighth music therapy session, and number 4 indicated the interview after the twelfth music therapy session. For example, (The caregiver 1) indicated that the quote was mentioned during the initial interview. The findings of the interviews were presented by inductive analysis method.

The caregiver stated that environment domain was crucial to the participant. She mentioned that it was the main problem that the participant usually complains about. The caregiver assured that music therapy alleviated the problem in environment domain from the participant.

*“She always mentioned that this place is not her home. She doesn't feel like it was”.* (The caregiver 1)

*“Since she is the only student with her condition, Muscular Dystrophy, she felt no one understands her needs and strengths”.* (The caregiver 1)

The caregiver witnessed that music therapy created hospitable environment for the participant. Moreover, participating in music therapy sessions provided new musical skills for the participant. This helps other people to see more of her capabilities.

*“She told me that music brings back her memory and atmosphere of her childhood. She sensed more happiness of being here since she doesn't have to go back home to play the music”. (The caregiver 2)*

*“People noticed her ability in music. They used to think that her condition would obstruct her ability, they stand corrected and show appreciation to her talent”. (The caregiver 3)*

In conclusion, the caregiver agreed that music therapy interventions helped improving the participant's quality of life in environment domain by creating home environment for the participant. Also, music therapy interventions provided new musical skills to the participant.

### **3.6 Discussion**

This study aimed to investigate the effectiveness of music therapy interventions on quality of life in environmental domain in a person with Facioscapulohumeral Muscular Dystrophy. The results showed that music therapy interventions could enhance seven facets out of eight facets of the participant's quality of life in environment domain.

According to the participant's WHOQOL-BREF-THAI scores, the scores during the first and the second measurement was increased five points in facets of home environment, transportation, opportunities for acquiring new information and skills, physical environment, and participation in and opportunities for recreation / leisure activities. During the last measurement, the participant scored five points in the facet of participation in and opportunities for recreation / leisure activities and four points in the facets of freedom, physical safety and security, and opportunities for acquiring new information and skills. As reported, music therapy interventions effected the participant the most in the facet of participation in and opportunities for recreation / leisure activities. The explanation for this finding is because, in this study, music therapy intervention were specially designed to meet the participant's ability and needs (Davis, Gfeller, Thaut, 2008). Most importantly, each intervention was entertaining and joyful. On the other hand, there were no change in the

facets of financial resources and health and social care: accessibility and quality because these facets were not consistent to the scope of music therapy. Anyhow, singing and playing instruments helped improving the participant's health. The participant's time of access to health and social care was decreased.

According to video recordings observation and interview findings, the details of quality of life changes were explained as follows.

In home environment and transportation facets, according to the participant limitation in physical movement, the participant could not travel to places as easily as she wished for, such as visiting her hometown. Therefore, environment domain was the domain that the participant complained the most, the caregiver reported during the interview. During music therapy sessions, the participant experienced that music created home-like environment to her and also could take her to places through her song choice, i.e. the participant requested to sing a song that she used to sing with her classmate in her high school. In this situation, music took her back to her hometown. She also requested more song with more creativity such as song about the sea, song about the mountain, song from Northern part of Thailand. These experiences that occurred during music therapy sessions can be referred to King (2004) that "Music is movable". Also, Clair & Davis (2008) support that "Music activities can contribute to a person's quality of life by creating a more positive experience than it would be without the use of music". Moreover, during singing and playing in music therapy session, the participant mostly looked outside the window from the multi-purpose room and later mentioned that, the view was more beautiful with the music.

In freedom, physical safety and security facet, music therapy interventions that were used to address this facet were improvisation and song choice. During improvisation the participant had an opportunity to explore the sound of each instruments and express her emotions freely in safe and nonjudgmental space. Moreover, the familiar sound of her song choice made her feel safe because "Music creates non-threatening environment" (King, 2004).

Furthermore, participating in music therapy sessions provided the participant an opportunity to acquire new music skills and leisure skills. During 12 music therapy sessions, the participant had opportunities to try new musical instruments which are the ukulele and

the xylophone. In process of acquiring new skills, I noticed that the participant mostly started her observation about the shape or the tone of the instrument to her familiar instrument. For example, she asked if the ukulele could play as guitar or if the xylophone used the same principle in playing as Thai instrument called “Ra-nad”. Later on, she mostly showed her interested in music theory of sound producing in each instrument and apply to the knowledge to her prerequisite ones. For example, during the ukulele playing, the participant wanted to play the D Major chord but in order to play, it requires three fingers on the neck, which was very difficult for the participant’s symptoms. She then counted the fret from open string and fined the D note by herself. Barksdale (2003) stated that music therapy has an ability in reinforce learning by the music therapist embed instruction in a music therapy activity. Also supported by another study that explained the benefit of acquiring new skill that sustained engagement in learning new skills in older adults enhance cognitive function of the brain (Park, Lodi-Smith, Drew, Haber, Hebrank, Bischof, & Aamodt, 2014).

In addition, acquiring new musical experience in her life; the eleventh music therapy session, the participant listened to the sound of the cello for the first time, inspired her with a new hope for the will to live. This statement could be supported by the study of Benzein, Norberg, & Saveman (2001) that conducted a study on hope, lived experience that affected the will to live in a palliative cancer patient, and quoted “hope is a dynamic experience, important to both a meaningful life and a dignified death”.

## **4. CONCLUSIONS**

### ***4.1 Conclusions***

Music therapy interventions of singing, playing instruments, song choice, lyrics analysis, and improvisation are useful and effective to improve the quality of life in environment domain of a person with Facioscapulohumeral Muscular Dystrophy. The interventions could improve the participant’s quality of life in environment domain in the facets of 1) freedom, physical safety and security, 2) home environment, 3) opportunities for acquiring new information and skills, 4) participation in and opportunities for recreation / leisure activities, 5) physical environment and 6) transportation. Singing and playing

instruments along with the participant's song choice created home environment to the participant. The participant stated that, being surrounded by the tune of guitar playing brings her the feeling of her home and could take the participant to places with the sound of her favorite songs. Lyrics analysis and improvisation provided opportunities for the participant to feel free, look outside the window and gaze at the view during the session. Music brought pleasure to the participant to appreciate the view of her dormitory's environment. Participating in music therapy interventions also provided new musical skills and leisure activities. To conclude, music therapy interventions enhanced the participant's quality of life in environment domain.

#### ***4.2 Recommendations for Future Studies***

According to my experiences during conducting the study and the results of the study, I would recommend for future studies to try working with multidisciplinary. For example, there were some limitations in this studies that could be improved by working with other related field.

Another recommendation would be the amount of the participants. It would be challenging and interesting to conduct a study of quality of life in a group of persons with various disabilities to see if the music therapy intervention would provide the same effect to each person in the group music therapy session.

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