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MUSIC THERAPY: ENHANCING COMMUNICATION BETWEEN FAMILY CAREGIVERS AND THEIR LOVED ONES WITH DEMENTIA

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Submitted in partial fulfillment of the requirements for the degree of Doctor of Arts in the School of Education New York University 1999
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Carol Gardner
Dedicated to
James Gardner
My Husband
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CHAPTER I
INTRODUCTION

This study grew out of my experience as a music therapist working in a nursing home with individuals with Alzheimer's Disease. I observed families who continued to be involved with their loved ones, visiting frequently and taking an active role in caring for their spouse or parent, while other families became discouraged and visited less and less, or not at all.

I wondered what it was that made the difference between these two types of families and if music therapy could help a family to stay involved with their loved one throughout the course of this debilitating illness. I also observed that music therapy could be used effectively with individuals with dementia. As deterioration increased and language was less viable, patients continued to relate through music. Where language failed them, music gave them back memories, however slight, of times, places, and people from their past. I began to question whether music therapy could be used to enhance the relationship between the individual with dementia and the caregiver.

I was inspired by testimony given in a 1991
hearing before the United States Senate's Special Committee on Aging. At this hearing numerous witnesses reported that music had made it possible for them to communicate in a meaningful way with their institutionalized loved ones. Senator Reid used the following example of a former staff member who used music with her grandmother who suffered from Alzheimer's Disease (Scovel & Wilson, 1992):

I love Grandma deeply and feel robbed by whatever demon has stolen her mind. Reaching back through the years I thought of the times when she held me in her arms and sang to me. Kneeling beside her wheelchair I sang 'our song' directly into her ear.

At first it was just a slight glimmer of recognition I noticed on her face. I was thrilled by that. And then she joined in. She sang the entire song, every word, and in harmony. And in the end tears rolled down my cheeks, she cried too, as if for the moment she realized her accomplishment.

We sing at every visit now. Sometimes when she sings I have her back, if only till the end of the song (p.46).

At this same hearing, Mrs. Lois Johnson described her participation in music therapy sessions with her husband who was an institutionalized Alzheimer's patient. She testified:

The thrill of seeing a little glimpse of the Tom I used to know was overwhelming. I knew he would never be well again, but music seemed to be the 'window to his soul' (p.47).

Some of the most moving testimony offered at this hearing had to do with the way in which music was used
to enhance communication and interaction with individuals with Alzheimer’s Disease and related dementias. The family members seemed to find some solace as music gave them one more chance to relate to their family member before death. The quality of life seemed to improve even if the progression of this disease could not be deterred.

Over the past several years I have worked with clients from age four years to age ninety-one years. Both in my work with children with behavior problems and my work with individuals with Alzheimer’s Disease, I have focused on the use of music therapy with families. As I observed families who were committed to maintaining a relationship with their loved ones, I became aware of the need to identify ways to support these families. My intent is to describe the impact that participation in music therapy has on the ability of families to maintain meaningful communication with their loved ones and how this contributes to quality of life for both the family and the dementia patient. I chose a qualitative method, and the study was conducted within a clinical setting, i.e. music therapy sessions within a nursing home, held jointly with the individual with dementia and family caregiver.

The initial focus of this study included the following questions:
1) What are the social and emotional problems that families of institutionalized dementia patients experience?

2) In what way does music therapy address the social and emotional concerns of families of institutionalized dementia patients?

3) What happens within the music therapy session? What are the common issues addressed, types of music used, and processes of interaction?

4) How does music therapy affect the quality of life for dementia patients and their families?

Although this study highlights the use of music therapy with individuals with dementia and their family caregivers, the process could be viewed through the wider lens of music therapy in terminal illness. Alzheimer's Disease is a terminal illness which has a slow, progressive course. Life expectancy may be as much as ten years following the initial diagnosis. During this time there is a steadily deteriorating progression. In offering support to families through this process, I became aware of the need to establish a long-term supportive relationship. This study describes the use of music therapy with two families over a period of one year.
CHAPTER II

PROFESSIONAL CONTEXT OF STUDY

Research Studies

Alzheimer’s Disease is a neurological disease which affects cognitive processes. It is a progressive and terminal disease. It affects persons in every economic strata and many of the persons affected have lived long, productive lives. Most of these individuals will be cared for in nursing homes in the latter stages of this disease.

Research indicates that taking care of an elderly demented family member has a negative impact on the health and well being of the caregiver (Rosenthal, Sulman, & Marshall, 1993) and that the impact is not lessened when the family member is placed in an institution. Families may experience relief because an accurate diagnosis has been made, and they are no longer responsible for care twenty-four hours a day. Caregivers continue, however, to feel vulnerable and helpless as they struggle to maintain a relationship with their loved one. The patient is dependent upon others but does not have the communication skills to relate to others or to express needs. Their ability to
interact with family members, facility staff, and friends slowly fades away.

The National Alzheimer Association reports that four million Americans have Alzheimer’s Disease. In response to this rapidly growing population, there has been an increasing interest in the use of music therapy with geriatric patients. In a review of the literature of music therapy from 1970-1988, Pricket (1988) identified six data-based studies conducted with geriatrics. In a more recent review Broton (1997) identified 69 journal articles in the area of music therapy and the dementias, 42 of which were empirical studies, and 19 of which were theoretical or philosophical papers describing music therapy techniques. These studies reflect an increase in research regarding Alzheimer’s and related dementia.

Scovel & Wilson (1992) documented proceedings from the 1991 United States Hearing before the Senate Special Committee on Aging. The testimony provided at this hearing was one of the factors that inspired me to undertake this study. At this hearing witnesses testified as to the efficacy of music therapy with the elderly. Witnesses included music therapists, physicians, professional musicians, and both patients and the families of patients who received music therapy services.
Two of the music therapists who testified, Alicia Clair and Suzanne Hanser, have done extensive research in the field of music therapy with geriatrics (Clair & Bernstein, 1990; Clair, 1991; Clair, Tebb & Bernstein, 1993; Clair & Hanser, 1995; Clair, Bernstein & Johnson, 1995; Clair & Ebberts, 1997; Hanser, 1990). In her testimony, Clair describes her work with severely regressed persons with dementia of the Alzheimer’s type. Patients are seen in a group setting of five to seven persons. Severely-regressed patients are described as those who are nonverbal or whose speech is unintelligible. They are completely dependent in all activities of daily living including toileting, grooming, and feeding. They are emotionally labile and behavior is often unpredictable and inappropriate. She describes a progression of disease in which these persons become more isolated and withdrawn, eventually losing the ability to walk, the ability to swallow, and dying of respiratory complications. This describes the typical progression of disease for an individual with Alzheimer’s Disease.

Clair testifies that throughout the progression of this disease patients retain the ability to respond to musical stimuli and interventions. This ability to respond to music is confirmed in other studies (VanderArk, Newman & Bell, 1983; Millard & Smith, 1989;
Redinbaugh, 1988). Responses often include singing in early stages. As the ability to sing deteriorates, ability to participate through rhythmic activities including dancing, movement, and instrument playing is sustained. In the most regressed cases, eye contact and facial expressions are common responses to music. Nursing staff and family members report that music is the only time they see all the patients, who typically wander aimlessly on the Special Care Unit, come into the day area and sit down. They report patients seem more alert during and after music sessions. Clair reports that she has developed music therapy practice protocols based on research conducted over a three year period.

I described similar experiences using music therapy with multi-handicapped patients with late stage dementia (Gardner 1990):

Typically these patients spend their daytime hours sitting in a solarium displaying little or no self-initiated interaction. As the tables are pushed out of the way, patients are brought into a circle, and the session progresses, a transformation occurs. In many cases, in the space of time that the group is conducted, individuals begin to interact with the therapist and, occasionally, with each other. They start to watch the activity of others, to follow verbal directions, to offer spontaneous reality-oriented verbal comments, and to engage in self-expressive music and movement improvisations (18).

Hanser (1990) worked extensively with elderly families within the community. She conducted an eight-
week music listening program for homebound older adults designed to help subjects cope with stress and overcome symptoms of anxiety, depression, and physical complaints. She found that these individuals maintained statistically significant improvements on standardized psychological tests over a nine-month period. She has expanded this work to address the needs of caregivers of loved ones with dementia.

Hanser and Clair (1995) collaborated on a research project in which they developed clinical protocols for working with patients with dementia of the Alzheimer's type and their family caregivers. Hanser describes music therapy techniques that she utilized with family members in a group setting. These include stress reduction techniques, singing, and improvisation. She presents a case study which illustrates benefits of participation in music therapy:

In a post-programme interview, Mrs. B and her daughter claimed to gain a new sense of their husband and father. Both of them reported greater self-esteem through developing their own abilities, and being able to see Mr. B performing so positively and creatively. They had not dreamed that it would be possible to enjoy their family time like this ever again. Yet during these eight weeks, they all had learned new skills and shared experiences which were some of the richest in their lives (p.353).

Clair developed a protocol that emphasized rhythmic participation. She found that severely regressed individuals were able to participate in
rhythmic ensemble using drums and other rhythm instruments, focusing their attention for seven to ten minutes, whereas in other settings they were unable to concentrate on anything for more than a few seconds. She invited the wives of these patients to attend group sessions, and describes their reactions:

Wives of the group members commented that they saw for the first time in a very long time, sometimes years, a glimmer of the man they had known and loved, the person who was really their husband, the man whose personality they only remembered. They said that music was the only way they had to make contact with that loved one, to capture a moment in which they could again belong with one another (360).

Clair, Tebb & Bernstein (1993) conducted a pilot study in which four couples met once per week for eight weeks to participate in a music therapy group. She measured caregiver’s feelings of isolation and self-esteem and found no statistically significant changes. She followed this pilot study with a study in which she measured frequencies of initiated and responsive touch by caregivers and care receivers in music therapy when compared with conversation. She also assessed caregiver’s perceptions of depression, burden, positive and negative affect, self-reported health, and satisfaction visits.

Both Hanser and Clair have added to the literature by conducting empirical studies with dementia patients and their families. They have developed clinical
protocols and attempted to demonstrate statistically significant improvements, as well as isolate variables that contribute to effective music therapy interventions. In reviewing this literature, it is often the spontaneous reports of caregivers that give me the greatest insight into the effectiveness of music therapy. Protocols provide a framework for describing music therapy sessions, are useful in training students, and conducive to gathering statistical data. Description of the therapeutic process that occurs when caregivers participate in music therapy with their loved ones with dementia is limited.

Clinical Approaches in Dementia

Chavin (1992) identifies common behaviors encountered with persons with dementia and offers suggestions for behavioral interventions. She describes many of the same problems I encountered in working with individuals with dementia. These behaviors include deficits in communication, anxiety, catastrophic reactions, reduced attention span, wandering and pacing, and uncommon reactions to common objects. Chavin offers descriptive examples from her experience at an adult day care center. Examples such as the following are helpful in understanding what the individual with dementia experiences:
Try to imagine being in the shoes of a person with dementia. Mrs. M is anxious because she doesn’t know where she is or who she’s with. She’s in a room with six other people. Five of them are older adults. The sixth is a younger woman who is sitting next to her in the circle, playing a guitar and encouraging the group to sing and play rhythm instruments. Can you imagine what’s going through Mrs. M’s mind?:

Where the heck am I? This isn’t home. We don’t do this at home. Do I know any of these people? No, I don’t. Where’s my husband? Do I live here now? What is this thing I’m holding and what am I supposed to do with it? That girl looks like she’s in charge. I’ll ask her what I’m doing here. I wish she’d stop singing and talk to me! (p. 11).

Bright (1988) also begins with the assumption that in order to provide effective intervention, we need to develop "an understanding of how it feels to the sufferer himself as he develops a dementing condition (p.5)" and what it is like to be a caregiver and to observe a relative as they gradually become demented. The current study adds to the available descriptive material regarding social and emotional issues of family caregivers and their loved ones with dementia, and how music therapy can be used to improve quality of life.

Many of the findings reported in Bright’s monograph were confirmed and replicated in this study. Bright states that with music therapy:

We can expect to build bridges between the isolated and lonely, and even if such bridge building is only a temporary measure, it is still worthwhile. We can hope to reduce aggression and
wandering. We can help to give a sense of reality to the environment together with affirmation of the worthwhile nature of the individual.

We can offer some measure of choice even for those who are in an advanced stage of dementia, and this too enhances the sense of individuality—often denied to a person in an institution.

We can hope to deal with some of the many and varied griefs and losses which flow from a dementia process, for both the individual, and more particularly for the family (p. vi).

This study supports much of what Bright presents in terms of benefits the loved one with dementia derives from music therapy. In the current study I take a small slice of what Bright presented and describe in detail the interaction that takes place between the loved one with dementia, caregiver, and music therapist. I focus on the relationship that develops when music therapy is offered in a one-to-one setting. Much of the literature available focuses on the use of music therapy in group settings (Chavin, 1992; Clair, 1991; 1993; 1995; 1997; Clair & Hanser, 1995). There is a depth and richness in a relationship which can be developed through one-to-one intervention and it is my hope that this study will stimulate an interest in music therapists who may be able to provide interventions to individual families within the institutional setting.
Methodological Considerations

Several authors have documented the need to develop alternative methods of studying the music therapy process (Forinash & Gonzales, 1989, Forinash, 1990, Aigen, 1991). Forinash & Gonzales (1989) called for an "alternative music therapy research method."

They make the following statements:

Although quantitative research methods have contributed significantly to the understanding of music therapy, these methods miss the very essence of what we experience as music therapy clinicians.

Our search is for a more fruitful method of describing clinical examples, a method that would include not only the significant implications and conclusions, but also what we term the "heart" of the work (35-36).

The foundation for the qualitative approach used in this study was laid by a group of music therapists who pursued alternative approaches to quantitative research (Aigen, 1992, Amir, 1990, Bruscia, Forinash, 1990, Gonzales, 1992, Kasyaka, 1991). This trend has gained strength in the last ten years.

A similar need for qualitative study has been noted in the literature related to caregiver stress. For the past ten years the needs of caregivers have become a prominent focus of gerontologists (Biegel & Blum, 1990). Research has focused on two primary areas: correlational studies which seek to determine variables associated with caregiver stress and the assessment of interventions.
Biegel & Blum summarized results from correlational studies. There has been considerable consensus regarding variables contributing to caregiver stress. The results of intervention studies have not been as conclusive. Toseland & Rossiter (1989) in a review of 29 studies found that although participants in support groups reported satisfaction, these reports were not supported by significant improvements on formal assessment measures. In evaluating the effectiveness of psychosocial interventions there is a discrepancy between the satisfaction that is reported by caregiving participants and the results of formal assessment tools. This points to a need for qualitative research in this area. Qualitative research is based on participant’s self-report and gives a broader perspective of the context within which these comments are made.

Music therapy has been demonstrated to be an effective tool in reaching individuals with severe dementia (Broton, 1997). The work of Clair, Hanser & Bright demonstrate effectiveness of music therapy with families. There is a need for more research regarding the use of music therapy with families. This study contributes a theoretical approach for the use of music to support families through the progression of terminal illness. My intent is to shed light on the process
which occurs when music is used within the context of a long-term relationship between the music therapist, the family caregiver, and the patient with dementia.
CHAPTER III

METHOD

Participants

Two mother-daughter couples form the basis for the case studies presented. I originally envisioned carrying out a series of music therapy sessions for six weeks to two months with approximately ten families. One of the first ethical issues that I faced was whether to base the number of sessions on a pre-established research protocol or on the needs of my clients. It became evident after the first two months of working with families that what was needed was a commitment to a long-term supportive relationship.

The first step in my research procedure was one of gaining access. In seeking participants for this study I placed an announcement in the Panhandle Alzheimer’s Society Newsletter and contacted staff at several local nursing homes. My initial contacts included Social Workers, Activity Directors, and Alzheimer’s Unit Directors. The newsletter announcement did not generate any response. My contacts with nursing homes were more fruitful.

I provided a written description of the study and
administrators were asked to sign a consent form. Details regarding space for treatment and scheduling were established. The nursing home staff contacted families and gave them my phone number and information about the study. They were given the option of calling me if they were interested. This procedure protected confidentiality as names were held in confidence and families were given the option of making the initial contact. Several families who were contacted declined to participate in the study stating that they could not make this time commitment.

A total of four families responded to the invitation to participate in this study. One family caregiver decided to withdraw from the study after the initial interview. Another family participated in a total of four sessions. Treatment was discontinued based on rapidly deteriorating medical condition of the patient.

Music therapy was begun with two families and it soon became evident that a long-term relationship was developing with these two families. The concept of redundancy (Lincoln & Guba, 1985) was used as a guideline to determine how long research data would be collected. After a period of one year descriptions of interactions within the music therapy sessions began to be primarily repetitive. It was determined that
redundancy had been reached within cases. The families continued to be involved in music therapy beyond the initial period of data collection. It is expected that the nature of this relationship and the music therapy interventions utilized will continue to change over time as this illness progresses and new data may be added as the study progresses. There is a richness and depth in the relationship developed with the first two families which provides sufficient material for this study.

Initial Interview

During the first telephone contact a preliminary screening was conducted. Vital information regarding plans for location of sessions, session times, addresses, and telephone numbers were obtained and an initial interview was scheduled.

The primary family caregiver participated in an initial interview, approximately 60 minutes in length, which was taped and transcribed. The purpose of this initial session was to understand the emotional journey in which this family member was traveling while caring for a family member with dementia. The interview format was open-ended. A thorough psychosocial history was obtained, focusing on the course of the disease and how it impacted on this family. A history of musical
preferences was included. This data provided the basis for answering my first research question regarding social and emotional issues that families face when caring for a family member with dementia.

Music Sessions

A series of music therapy sessions was scheduled with the individual with dementia and her family. Sessions were approximately 30-60 minutes long and held on a weekly basis. A chapel was utilized that provided privacy and ample room for family sessions.

I utilized interventions which are within commonly-documented techniques used with elderly. These include singing, listening to tapes, instrument playing, movement, dancing, and discussion. Musical accompaniment was provided primarily with guitar. Instrument playing included use of small rhythm instruments, drums, and omnichord.

The content of each session was determined by individual needs. A repertoire of musical interventions was developed which facilitated interaction. This repertoire was unique for each subject pair. I assessed the type of music to be used based on subject's musical preferences. My intent was to facilitate interaction, expression of feelings, and exploration of therapeutic issues. Process notes were
written following each session.

**Inductive Data Analysis**

Sources of data for this study included interviews with family and staff, interaction with and observation of patient, and music sessions with family and patients. Data were collected in the form of written notes, logs, cassette tape-recordings, and video recordings. Each interview and music therapy session was video-taped. These tapes were reviewed. Partial transcripts and interpretive notes were written. I wrote notes in the margins of transcripts and then outlined these notes, noting themes that were repeated in more than one session. This material, along with my process notes and logs, was sorted into categories. I experimented with different ways to group and organize this material until a structure began to present itself. This material was used to describe sessions and identify benefits derived by participants.

I then reflected on the process that occurred as I worked with families. I borrowed several terms from related literature which helped to summarize my approach to working with families. These terms included "honoring" the loved one with dementia, and "empowering" the family caregiver. I then reviewed videotapes and logs to identify moments in which I saw
this process of honoring and empowering within the
music therapy sessions.

Emergent Design

As in most qualitative studies, the design of this
study evolved as the focus of the study became more
specific. The flexibility allowed me to narrow my
participants to two case studies which I followed over
a long term. It allowed me to structure music therapy
sessions based on the moment-to-moment needs of my
clients, rather than follow a strict research protocol.
It allowed me to experiment with different ways of
analyzing data. When the data analysis was completed,
I took a step back from the data to see what the
significant conclusions were and to utilize the data as
a framework to draw a more global picture.

Quality Criteria

In designing and carrying out this study I
utilized quality criteria drawn from the work of
Lincoln & Guba (1985) and Erlandson (Erlandson, Harris,
Skipper, & Allen, 1993). Erlandson et. al. outlined
the following steps in establishing methodological
accuracy, which is referred to as trustworthiness. The
following terms are defined and then outlined in terms
of how these conditions were fulfilled within the
current study.

1. Prolonged Engagement:

An extended time period necessary to develop rapport and overcome biases introduced by the newness of the relationship, and biases due to describing a situation that is influenced by a particular time-limited event.

2. Persistent Observation:

A process of determining what is relevant to the study and pursuing different ways of interpreting data through constant and tentative analysis.

3. Triangulation:

Data that are collected from different sources and different points of view, and then compared. This can involve the use of multiple sources of data, methods, investigators, or theories. It allows for discoveries that might not otherwise emerge. The greater the degree of convergence from different sources, the greater the confidence that can be placed in the observed findings.

4. Referential Adequacy:

Materials that give a holistic view of the context. This may include videotapes, photographs, and documents that aid the reader in understanding the researcher’s analyses and interpretations. These materials help the reader to understand the context in which the study was conducted.

5. Peer Debriefing:

Periodical review with a professional peer outside of the context of the setting. This peer will monitor the progress of the study, review data, test working hypotheses, and emerging design, and listen to the researcher’s ideas and concerns. This debriefing encourages on-going problem-solving, venting of feelings, and feedback which may influence the emerging design of the study. A written reflective paper following each session summarizes the discussion and outlines plans made.
6. Member Checks:

Reviews by participating members of the study to provide feedback regarding the results of the study. Member checking provides credibility and is done throughout the study. It may include summarizing the data at the end of an interview, and inviting the respondent to give feedback; or providing copies of various parts of the study to various participants and asking for a written or oral commentary on the contents. Before submission of the final report, a copy of the entire study is provided to a review panel of participants for feedback. This feedback is then incorporated into the body of the report.

7. Reflexive Journal:

A diary which documents the process that the researcher goes through in conducting the study. This includes a record of the researcher's schedule, logistics, insights, and reasons for methodological decisions. Entries are made on at least a weekly basis.

8. Thick Description:

The context of the study described in enough detail that the reader can determine what elements and conclusions are transferable to the setting in which they are working. Data must be described in enough detail so that the reader can experience the context as though they had been there.

9. Purposive Sampling:

Participants are selected by emerging insights about what is relevant to the study and both typical and divergent data are sought to maximize the range of information obtained about the context.

10. Audit Trail:

Documentation of the process by which the study was completed. The audit trail allows one to review the raw data and observe the process by which the researcher analyzed the data, and shows the timeline of all the interviews, sessions, and meetings that occurred as the study was conducted. The audit trail is helpful not only to those reviewing the study but also to the researcher in
that it aids in the organization and focus of the study.

All of the ten steps above were included in the design of the present study as outlined below.

**Prolonged Engagement**

One of the first ethical considerations encountered in designing this study was the length of time that data would be collected. During many experimental research studies, a common length of treatment is six to eight sessions. In the current study data collection and analysis was continued in an open-ended manner until redundancy was achieved.

**Persistent Observation, Purposive Sampling, Thick Description**

Some of the steps described above were built into the emerging design (persistent observation, purposive sampling). Purposive sampling procedures were utilized. The method of data collection, written transcripts, notes, and video tapes provided material that could be reviewed repeatedly. Throughout the writing of this report different ways of interpreting and analyzing the data were pursued in an effort to glean as much information from the data and produce as thick a description as possible.
Peer Debriefing, Reflexive Journal

Peer debriefing included meetings with professional peers both within the field of music therapy and from outside related fields. I established a network of professional peers who were interested in my study that I utilized at different stages of research. A reflexive journal and summary of peer debriefings were maintained, as well as a log of meetings and an on-going timeline documenting the process of conducting this study.

Triangulation, Member Checking

Triangulation was accomplished by including data from multiple sources. Data were collected from the family, in the form of interviews and written feedback, from consultation with staff, and from observation of videos. Each of these different points of view, i.e. the therapist's, the family's, the dementia patient's, and the staff members' was included in the study.

Member checking was accomplished by reviewing interpretations of data with participants. Interviews with the family provided one method of gathering feedback from participants. As I began to interpret and summarize the data, copies of various parts of the study were reviewed with the participants and they were asked to provide commentary on the contents. This
feedback was then incorporated into the body of the report.

The families became equal participants in telling their story as they participated with me in disseminating results to the staff in the form of in-service presentations.

Audit Trail

An audit trail was maintained with the above documentation of meetings and timeline, and reflexive journaling. Raw data in the form of video tapes, audio tapes, session notes, logs were filed and catalogued. A notebook was maintained with typed copies of all process notes, transcriptions, and initial data analysis. This helped to organize material so that I could easily review data as the focus of the study was refined.

Summary

The method chosen for this study allowed me to take an in-depth look at a clinical area in which I was interested and felt had the potential to improve quality of life both for family caregivers and their loved ones with dementia. The concept of allowing for an emergent design permitted me to adapt procedures to the needs of the families that I worked with. The
concept of encouraging families to be equal participants in this process served to empower them. Therefore, the research method strengthened and complemented the therapeutic process.
CHAPTER IV

FAMILY PROFILES AND DESCRIPTION OF ISSUES ADDRESSED IN MUSIC THERAPY

One of the hallmarks of Alzheimer's Disease is short-term memory loss which affects the person's communication skills. Imagine what it is like to visit your loved one. The person that you grew up with, were married to, or knew as a grandparent has changed drastically. You know they have something in mind, they start to say it and the sentence just hangs in mid-air. They can not find the words. They will talk, and you can sit there and nod your head, but the phrases of their conversation do not fit together. What do you say when you come to visit your loved one in a nursing home? What can you share with this person? Conversation is limited, and for the most part one-sided.

It is into this context that I entered as a music therapist. The following chapter describes initial interviews with family caregivers and music therapy sessions held with two mother-daughter dyads: Connie and Mary Jo, and Doris and Musa. Initial interviews and music therapy sessions took place in a beautiful new retirement home and skilled nursing facility. We met in
a chapel with a lovely stained glass window. The chapel had ample room for a family group and afforded us privacy with a view of grass and trees outside a large picture window. During initial interviews with family caregivers, Doris and Connie helped me to understand the social and emotional issues which they faced as they provided care for their mothers, Musa and Mary Jo. They described unique aspects of their mothers’ personalities, and the way in which this progressive disease affected their relationships. The information they shared in these first interviews served as a foundation and rationale for my intervention.

Connie and Mary Jo

Initial Interview With Family Caregiver

Connie was divorced and had two grown sons, ages 19 and 26, at the time this study began. Following the divorce, Connie returned to teaching in secondary education. Her younger boy was in college, but still periodically lived at home. Connie juggled full-time employment with being a single mother, and the primary caretaker for her mother. Mary Jo, Connie’s mother, was also a school teacher for twenty-eight years, with a master’s degree in education. At the time this study begins, Mary Jo was 73 years old. She was a slender and
fragile appearing woman, who was always neatly dressed and groomed. She responded to introductions with a smile and a warm and gracious manner. Mary Jo was a resident on the Alzheimer’s Unit. She was ambulatory and exhibited many symptoms that are characteristic of Alzheimer’s disease: motor restlessness, memory loss, communication deficits, loss of ability to care for oneself, in addition to being diagnosed with Parkinson’s Disease. Mary Jo constantly held a tissue in her hands which she twisted and folded. She had a constant drool as the result of lack of facial muscular control. Connie often took the tissue and wiped the drool from her mother’s chin.

Mary Jo participated in activities on her unit for brief periods of time. She did not tolerate sitting, and often felt a need to get up and walk. She had difficulty sitting, and it could take several minutes to physically guide her into a chair. I observed Mary Jo playing bingo. She was not able to use objects functionally, no longer aware that the red chips are used to cover squares on the bingo card. She stacked them, and kept removing them from the card and putting them away in the box, concerned that the table needed to be cleared. Mary Jo carried on conversations that were difficult to follow and had little connection with the present, often referring to her former students.
Connie helped me to understand the emotional and social issues that a family caregiver faces in providing for a loved one with dementia. She talked about issues such as role reversal and personality change that occur with dementia, and described the feelings she experienced as she witnessed the progressive dementia in her mother. Connie brought her mother to live with her after her father died of prostate cancer. I asked Connie to describe some of the ways that Mary Jo had changed during the course of this disease. She shared some of the effects that role reversal and personality change had on her relationship with her mother:

The role reversal was real difficult in the beginning (tears). In fact, I’m real surprised at my reaction. Very surprised. I haven’t cried about this in a long time. Of course I haven’t been asked how she was before, and that makes a lot of difference.

I asked Connie, "How is this different from the mother you grew up with?" This was also a hard question. Connie described some of the changes she had seen in her mother: "I used to go home to be nurtured and taken care of. My mother is more self-centered now than she’s ever been in her life. She was a source of strength and support. Her needs were never put in the forefront until now."

One of the favorite memories that Connie had of her mother was the joy that she received from interacting with her grandchildren. Connie described how her mother
and father looked forward to their visits and how excited they were when they knew the grandchildren were coming to see them. Mary Jo knew what the boys liked to eat and had everything baked for them when they arrived. "She liked to send care packages to the boys, ...without fail, at Halloween, at Valentines. She never let a holiday go by when she didn’t send these big care packages for the kids."

Connie reported that Mary Jo was always extremely active:

She was always extremely active and her sources of activity were the teaching profession, her family and her church, and when these were stripped from her...It was a real difficult transition for her to make.

She no longer had the ability to concentrate on sewing, for example, needlepoint or handwork of any kind. Cooking had always been one of her loves, and she was no longer able to concentrate long enough to cook.

Those things that she got joy from, one by one, were disappearing.

Connie continued, "It was real hard to watch that happen, because she was still able to express the frustration of no longer being able to do those things. One of the things that I witnessed daily, with her being home, was her frustration at no longer having any goals." Mary Jo would frequently say "I don’t have any goals."

Connie described her feelings the first time she came to visit and her mother did not recognize her, and
shared how she coped with this:

The first time I saw it, it was very painful. When I came and it was like, "Oh, you're here, big deal," and she was on her merry way. I had to just realize that this was not the Mom I had grown up with and that it was really not a good idea for me to expect her to meet my needs anymore, you know (laughter).

When I asked about her role as a caregiver and how often she visits her mother, Connie shared the following: "The most I miss is every three days. I have missed three days in a row. I'm very uncomfortable when this happens."

To be real honest, I think part of that is I put myself in her place and I think, gosh, what if that were you, and you had been totally removed from the environment of your life, and you were in a strange city, with all your friends eight hours away. I just couldn't do that. I would consider that abandonment.

Connie described a feeling of helplessness that she encountered when taking care of her mother at home. She would come home from a day of teaching and this would be the time of day that Mary Jo was most agitated. "That 'sundown syndrome' made it really difficult for me, because from 4:00 until about 7:00 or 8:00 was not a good time for her. And I think the thing for me was the helplessness. That I couldn't make it better for her."

Though most of my work has been with the primary caretaker, the placement of a loved one in a nursing home affects an entire family. The progression of dementia takes place within a multi-generational setting:
children, spouses, and grandchildren are directly affected. Connie had two boys. Her youngest son was still living at home when Connie brought her Mother into their home to care for her. I asked Connie about her children, and she stated that they each had a unique way of adjusting. Her oldest son seemed to be able to accept Mary Jo's illness better, since he was not living at home at the time Connie brought her mother there. He did not witness some of the dehumanizing things that her younger son did.

My youngest son, from my point of view, has anger, and some resentment, and I think he expresses it by really detaching. He witnessed things that were very unlike her.

Her hallucinations bothered him a lot. Her drooling bothered him a lot. Her medication was messed up for a while. She would appear half-dressed and that was frustrating for him. She was always a private person and that was something that was very unusual for her. And it was something I couldn't always be on top of.

Connie stated that it was very emotional for him, and hard for him to witness these things happening to his grandmother. "It is still difficult, I think, for him to accept her illness. He would much prefer her to be the grandmother that he once had."

Connie took full responsibility for being the primary caregiver for her mother. In my initial telephone conversation, I asked Connie if she would be going out of town for spring break, and she said, "No, I am my mother's primary caregiver." She was conscious of
not wanting to shift this burden to her children, stating that she was careful not to become dependent on her sons. "I try real hard not to force the kids to come, and that’s pretty hard to do sometimes. I want them to come out of love for her and not out of guilt. Her care is my primary responsibility, not my children’s."

Connie talked about how mysterious this disease is, and how she would have liked to be able to understand what her mother was experiencing. "There’s a part of me that finds it very fascinating, and there’s a part of me that finds it very sad to witness." The impairment in communication makes it difficult to know what this disease is like from the point of view of the loved one with dementia. Connie explained how distressing it could be not to understand what her mother was experiencing.

I’d like to know what’s going on. I’d like to be able to see what’s happening and to know. Because none of us can crawl into the skin of another person and truly identify with their pain, whether they are in this unit or walking on the street. We don’t really have that ability. Her memory is so mysterious, what’s wrong with her is so mysterious, and I’ve read everything I can find and nobody knows, and it’s distressing.

The primary caregivers who participated in this study were individuals who chose to remain actively involved with their loved ones in spite of the emotional and social issues described above. In my interviews and tapes of music sessions I was struck by the sacrifice these family members made and by their openness to
experiencing both the pain and the joy of caring for a loved one with dementia.

Connie described a sense of fulfillment that she derived from being able to take care of her mother:

I do things for her now, that I realize I’m doing for myself, to make me feel better. Such as her laundry. She could care less who does her laundry. But I have to do that. For right now I do. I just have to feel like there is still something that I can do. So there is some fulfillment in that, too.

Connie shared with me one of the sources of her strength, which was the ability to appreciate the things that her Mother could still do:

I am very, very, very grateful that my mother can still enjoy God’s beauty, because she can. Her eyesight is still good and her hearing is still good. She can still appreciate birds, and trees, and flowers, and music.

She also described how her faith helped her to cope:

I have to remind myself that I didn’t cause these diseases, and that I can not cure them, and that if I stay close to God, He’ll give me the strength to do it daily.

I really believe that God will prepare me, daily, for the changes that are bound to occur, because both of my mother’s diseases are not curable, and they’re progressive. For that reason, I think that, as we go along, and we walk this walk, that it will be OK.

Music Therapy Sessions

At the time this study began, Mary Jo was ambulatory. She was thin, frail-looking, well-groomed, and had a delicate nature about her. She was a resident on the Alzheimer’s unit, where there was a daily
structured program, but the music therapist reported she had difficulty engaging Mary Jo for any length of time. She would sit for brief periods of time, become restless, and leave the group to pace or wander on the unit. She was frequently anxious about something that needed to be done, and often returned to the days when she was a school teacher. Mary Jo had a vague, withdrawn quality about her.

I have chosen to describe our first session in detail because it demonstrates many of the problems encountered and strategies used in attempting to communicate and maintain a relationship with a family member with dementia. My observations begin with the first contact. Quite often important information is gathered as I am setting up for a session. Preliminary greetings provide information about the family member’s mood, current state of health, and set the tone for what kind of music needs to be presented in the session.

Overcoming Word Finding Difficulty and Disorientation

As I set up my equipment, Mary Jo and Connie were sitting together. Mary Jo was talking, but her conversation was tangential. The expression on her face was vague, there was no eye contact, and there was no thread of logic which could be followed. I drew my chair close to Mary Jo’s and took her hand in mine, providing
auditory, visual, and tactile cues. As I introduced myself and picked up my guitar, an element of novelty was introduced. Mary Jo came into focus, became aware of what was happening in the moment, and responded with an appropriate greeting.

Much of a family caregiver’s time is spent sitting with a loved one, nodding one’s head and agreeing with whatever the loved one is talking about. This can be a frustrating experience as the conversation and interaction is not meaningful. There is a sense of loss in that the person who was known and loved is no longer there. Previous means of communicating, interacting, and sharing affection are no longer available.

Mary Jo has gradually lost her ability to communicate and often does not know where she is. The following transcript demonstrates the problems I encountered as I attempted to engage her in conversation. I stated:

I brought my guitar today so we could do some music. Mary Jo responded positively stating, "Good! Our pastor’s wife is a pianist, so beautiful, and she had a guitar."

I asked, "Would you like to start with a hymn? Would you like to start with ‘Amazing Grace’?" Mary Jo responded, "Listen I don’t know. I want her to be the guide."

I reassured her, "You can just listen if you want to." Mary Jo nodded her head and stated, "They’ll like that, especially the students."

Mary Jo responded with a statement that was loosely
connected to the question that I asked. Asking a person with dementia to make a suggestion for a song is often not successful. It requires that they retrieve words, which triggers word-finding problems.

Her response also illustrates her disorientation to time. She referred to her students as though they were here in the present. In my initial interviews, family members made reference to the fact that their loved ones were often in another place, another time when they came to visit.

I encountered further blocks in our communication as Mary Jo was unable to complete even one sentence. I asked, "Did you sing spiritual songs with your students," and she replied, "Well, there have been. Children have been great, there have been so many, chat, that, especially in college." She started a sentence, and the sentence just trailed off, as she could not find the words to express what she was trying to say.

Reflecting Pacing and Wandering

As our session continued, Mary Jo became increasingly restless. She was unable to stay in her chair and got up to walk around. Mary Jo stated, "I've got to walk. I'm going to walk around the room." She got out of her chair with some assistance from Connie for balance. As Mary Jo walked, I improvised a walking theme:
Walking, walking, Walking, walking
See the pretty grass, and see the pretty trees
Walking, walking
See the pretty grass, and see the pretty trees
Walking, walking

Mary Jo returned to her seat and I continued singing, "and thank-you for the sunshine that came out today." Mary Jo smiled as she sat down, I continued:

Chased away the clouds today
Thank-you, Thank-you
Thank-you for the sunshine
Thank-you for the flowers
Thank-you for the grass
Thank-you for the sunshine.

It is difficult to imagine what it must feel like to be compelled to get up and walk or pace. To feel an increasing restlessness and anxiety that seems to build up gradually until you just have to stop, break away from whatever is happening, and walk to discharge this tension. The music provided a positive frame for this activity.

Reducing Agitation

As our session continued, Mary Jo became increasingly agitated, stating, "Seems like I just can’t get settled." Connie commented that it was late in the afternoon and explained that her mother often became restless at this time of day. I began to sing "Kum-Ba-Ya". Mary Jo responded to the soothing quality of this
spiritual folk song.

One of the strengths of music is that one can be affected just by listening. Mary Jo was not singing, she was not being asked to perform any complex tasks involving motor skills, she was just listening. And even though her cognitive abilities were limited in many areas, she could still appreciate and respond to the soothing quality of music.

Connie sat on one side of Mary Jo and I sat on the other side and as I played the guitar, our voices blended together. I could feel the physical vibration of our voices filling the chapel and there was a sense of unity inspired by the spiritual quality of this song. As we sang, the music surrounded Mary Jo in a soothing envelope of sound.

Stimulating Memories and Reminiscence

In my second meeting with Connie and Mary Jo, we started the session reminiscing about Mary Jo’s family. Connie chose "Down By the Old Mill Stream" from a songbook that I provided. As the song ended, Mary Jo made the following comment,

I had a sister who played, and she just played and played and played until she was just exhausted, and she’d stop and all...

I asked Mary Jo if she remembered the marathon dances that were held during the depression. She
replied,

No. I didn't know anything. My mother was very back when it was considered, not singing was not, but mother never did let us go dancing, that I remember, and she played the piano.

Connie was surprised, and asked, "Mother Kate played the piano? I didn't know she played the piano!" Mary Jo replied, "Yes! That was our special treat to hear her".

There were eight girls in Mary Jo's family. Two of the girls, Madelaine and Adelaine, the twins, got to take piano lessons. Connie asked Mary Jo what Madelaine and Adelaine would do when it was time to wash the dishes. Mary Jo stated:

It was really a treat to come in and not do the dishes. Why they got preference because we didn't have very much money. Our grandfather was the one that saw to it that we got the first lessons. He started out with them. One would play awhile and then the other, and by the time they got down to us they didn't have any time left.

The music therapy session provided the context for reminiscence. The song Connie chose brought back memories of the role that music played in Mary Jo's family. With the cues provided by the context of the music therapy session, and memories evoked by familiar songs, Mary Jo was able to recall a time before the onset of dementia when she was healthy and surrounded by her family. As the family gathered around the piano there was a sense of closeness and sharing. Mary Jo was able to connect with these earlier memories and feelings through music.

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Facilitating Awareness of the Present

As this session progressed, there was an incident in which Mary Jo connected with a memory that was not so pleasant. We were singing "Casey Would Waltz With the Strawberry Blond" when Mary Jo began to get restless. She interrupted the song, looking over her left shoulder and stated, "Don’t you think we ought to go up there?" She repeated, "Don’t you think we ought to get up there, to the platform?"

Despite our attempts to verbally redirect her, Mary Jo was convinced there was a rehearsal going on for a school production and she needed to get up there and help. She became more agitated stating:

We’ve got a weak group this year. And they didn’t even call me. I didn’t anymore know what was on the program than not.

Connie and I made several attempts to reflect Mary Jo’s feelings and validate her concerns, but she became increasingly nervous. At one point she looked out the window and stated, "I don’t know why, but you know that thing is all colors." She may have been experiencing a visual distortion or hallucination. Connie reassured her, "What you’re seeing is your reflection in the glass. Is that troubling you?" Mary Jo replied:

I’d be embarrassed. She didn’t even come early or anything...and it’s all right, and I’m sure she knows the activities, but they just cover you, and to help you with the...

It must be a frightening feeling to remember anxious
moments that have occurred in your life and replay them as though they were happening in the present. Agitation and the fear that accompanies disorientation is a common symptom of Alzheimer's Disease. It is not unusual for individuals with dementia to replay anxiety-provoking memories over and over.

At this point in the session Connie and I began to sing familiar hymns, something soothing in an attempt to distract Mary Jo and decrease her agitation. Mary Jo calmed and smiled as Connie and I sang "Amazing Grace." This was followed by "Kum-Ba-Ya." I sang two verses, and then asked Mary Jo to fill in words to the song. Connie prompted her mother, saying:

If you were praying what would you ask for Mom? Can you think of something you would ask God to give you?

Mary Jo responded, "Yeah." Connie asked, "What would that be?" Mary Jo responded, "health." I sang the verse, "Give me health Lord, Kum-Ba-Ya."

I supplied the next verse, "Give me love, Lord, Kum-Ba-Ya." I continued singing, "Give me peace" and Mary Jo took a deep breath. I asked her what else she would ask for. She replied, "Well I just miss the family."

This was a powerful moment of connection. In the midst of a session in which Mary Jo was disoriented and agitated, the music helped her to become aware of what was happening in the present, and to communicate and relate in a meaningful way with Connie.

In describing Mary Jo, Connie talked about how much
she enjoyed visits from her grandchildren. She described the many loving things that Mary Jo did to keep in touch with them and demonstrate her love for them. Through the music, Mary Jo was able to identify the two things that are still most important to her: good health, and her family.

**Encouraging Active Role of Family Caregiver**

Connie was beginning to feel more comfortable in the music therapy setting and was taking a more active role. She was more comfortable singing with me and took the lead in choosing songs. She played an integral part in sessions by facilitating reminiscence and clarifying instructions for her mother as we sang "Kum-Ba-Ya." She connected emotionally with the intimacy and spiritual feelings of this moment. We were becoming partners in providing interventions for Mary Jo. I encouraged this by picking up on Connie’s suggestions and encouraging her to sing with me. As our sessions continued, Connie increasingly took the role of co-facilitator

**Fostering a Sense of Accomplishment**

In the following excerpt from session seven I introduced the use of a metal xylophone. The use of instruments gave us another modality through which we are able to communicate with Mary Jo. The xylophone
to sing with me. As our sessions continued, Connie increasingly took the role of co-facilitator

**Fostering a Sense of Accomplishment**

In the following excerpt from session seven I introduced the use of a metal xylophone. The use of instruments gave us another modality through which we were able to communicate with Mary Jo. The xylophone consisted of fifteen metal bars ranging from A to C2, so that both minor and major scales were available.

We began by exploring the sound of the xylophone. The tone bars have a gentle, beautiful timbre, and Mary Jo tentatively explored this sound. Her response was positive. She was willing to play, and she stated that it was fun to try. Connie and I took a supportive role. Mary Jo was intent on exploring this new modality, and we listened, providing affirmation and support.

Mary Jo’s playing at this point was similar to her verbal conversation. The notes were randomly selected. They were not tied together by any rhythmic pattern or central melodic theme. The music she made was tangential, in much the same way that her conversation was tangential. Connie assisted Mary Jo in playing the xylophone, and I began to compose an accompaniment, singing:

Mary Jo, Mary Jo plays the bells with me
And I sing as she plays, Plays the bells with me.
arm movements. I reflected her movement, playing long, sweeping strums on the guitar. For several beats, my strum and her glissando matched beautifully. I waited for Mary Jo to initiate action, and matched her rhythm. Connie exclaimed:

You’re making the music! You and Carol together! When you do like this (made motion of glissando), she strums the guitar (demonstrated motion), and it sounds real nice.

There was an excitement that all three of us felt in this moment. After much tentative exploration the music came together. We were playing in a way that was rhythmically and harmonically synchronous, and there was a mutually satisfying exchange. For the space of about ten minutes, Mary Jo was connected with the present. She was using objects functionally and her facial expressions and comments indicated that she derived pleasure and a sense of accomplishment.

Summary

Mary Jo participated in music therapy for ten months. Throughout the sessions she maintained a graciousness and gentleness in those moments when we connected through the music. She lives, however, in a world in which much of the time she is either vague and withdrawn, or experiencing anxiety and agitation. Music therapy provided us with a modality through which we were able to connect with that part of Mary Jo that is
gracious, gentle, and full of love for her family.

Doris and Musa

Initial Interview With Family Caregiver

Doris and Musa were both senior citizens. Doris was in her early seventies and Musa was in her nineties. Doris was an attractive woman with a cultured background. She enjoyed travel and opera. She was warm-natured and spontaneous and enjoyed a close relationship with her mother. Doris had been a widow for eight years when her father died. When she found that her mother was not eating, and not taking care of herself, she brought her mother to live with her. She cared for Musa in her home for seven and one half years, and described their relationship: "I loved having her in my home. We went a lot of places together and enjoyed each other. She was not only my mother, but my best friend!"

The decision to place Musa in a nursing home was not an easy one. Doris began to have health problems and her doctor eventually told her, "You can’t take care of her anymore." Doris stated that she hated to move her mother and never could have done it herself. One of her daughters came down and took care of it. Doris was in bed herself at that time and stated, "I could take care of myself, but I couldn’t take care of
her. So it was sad." Doris visited her mother two to three times per week.

At the time this study began, Musa was a resident in a skilled nursing facility. She was non-ambulatory and used a wheelchair. She spent most of her day sitting in the hallway or day area with little awareness of what was going on around her. She had limited eye sight and her hearing was impaired. Musa occasionally was found visiting with another patient, but for the most part she remained isolated, rarely initiating interaction with staff or peers. She had some pain from arthritis and complained of discomfort as a result of long hours sitting in a wheelchair. She was able to make her needs known and continued to be continent, relying on nursing assistance to transfer her from the wheelchair to the toilet in her bathroom. She fed herself, but was dependent on staff for all other activities of daily living such as dressing and bathing. Musa rarely joined in activities, but did enjoy music.

Doris stated that Musa once loved books and travel; Doris had bookshelves made to house her mother’s extensive collection. In describing Musa’s history, Doris shared, "She was valedictorian of her class - a very, very intelligent person - and that’s one reason why the way she is now tears me up so
badly." She went on to describe her mother as being very popular with interviewers because she was bubbly and loved to tell stories of her past. I asked Doris if she would still describe Musa as bubbly at times, and she replied, "No, I don’t get that bubbly part of her anymore. I just feel like it has gone away with her mind. I miss her."

I asked Doris what her visits with her mother are like now. Doris replied, "I push her up and down in her wheelchair, and we usually end up sitting and talking, and I just go along with what she says." Musa was often disoriented to time, place, and person; talking about people and times in the past as though they were in the present. Doris described these conversations, "If she is somewhere else, I listen to her, and I go along with whatever she says. She always talks about working. She loved her jobs; she loved to work. One time she imagined she was teaching at an Air Force base in the countryside of France. Often she is an actress and everybody out there is part of the group of actors, and she is rehearsing a play." Musa often asked about Doris’ husband, and could become quite upset because she did not remember that he died seventeen years ago. She wept and demanded to know why no one told her about his death. Musa talked about conversations that she recently had with people who
passed away years ago. Doris stated, "I go right along with that."

In talking with Doris I observed that taking on the role of caregiver made a big change in her life. She replied that it did, because she was not able to travel as much. As Musa’s illness progressed she had to have someone come and stay whenever she left, so it was easier to stay home. Doris visited Musa at least twice a week and sometimes three times.

She thinks I come a long way to see her (laughter). She always tells people, "This is my daughter who travels all the time," (laughter) and I haven’t been any place, hardly.

Doris used to enjoy going out of town to see the opera, but she has given up traveling since she took on the role of caregiver. Doris stated, "It was worth it. I just felt like that was what I was supposed to do and I really felt called to take care of her."

Doris agreed that her role of caregiver gave her a sense of purpose, a new direction, perhaps at a time when that was what she needed.

I asked Doris what interested her in participating in this study and she replied:

I think what interested me was that it was something that we could share. I’m not musical, but if we could find a bridge through which I could reach her, I would like to have that because I feel like she’s fading away.
Music Therapy Sessions

In working with Doris and Musa I encountered many of the same problems that were identified in the sessions described above. Musa also suffered from cognitive impairment which resulted in disorientation, deficits in communication, and agitation. In spite of these obstacles, there was a pervasive sense of sharing and communication that occurred within the music therapy sessions. One of the unique qualities that Musa brought to our sessions was her sense of humor. Doris reported in our initial interview that Musa had a bubbly personality, but she felt she no longer saw that side of her. It was like the mother she once knew was fading away.

Bypassing Auditory Processing Deficit

Doris was faced with a difficult task when attempting to communicate with Musa. Musa had difficulty remembering where she was and what was happening in the present. She had problems finding the words to say what she wanted to say, and to complicate matters even further, she had a hearing loss. Doris compensated for this hearing loss by speaking loudly and limiting her verbal conversation to information that could be communicated in short, simple
The following excerpt from our second session demonstrates the difficulty Musa had in processing verbal language, and the tangential nature of her speech. I asked Musa:

What song would you like to sing today? Musa replied, "What, What?" Doris rephrased the question, speaking slowly and loudly, "Is there a song you would like for her to play?"

Musa replied, "Any of them. They’re all new to me. Since I don’t have a group. So, therefore, we don’t sing. They all split up. They got married and had babies and then they learned how to sing a different tune."

Musa had difficulty hearing and responding to verbal conversation, yet she heard music and remembered the words to songs. Music seemed to bypass areas of the brain that were affected by cognitive impairment.

Encouraging Creativity and Playfulness

Singing formed the basis of much of what we did in music therapy sessions with Musa. Her favorite song was "K-K-Katie" which we sang every session. When I first introduced this song, Musa joined in with a smile and sang with us, her voice clear and confident. Her comment was, "Now that’s what I call music!" She consistently considered "K-K-Katie" to be her favorite and I often used this as our opening song.

Musa’s creativity and playfulness was something we encouraged throughout our sessions. Doris and I both
gave Musa positive feedback in the form of praise and acknowledgment when she added her own unique words to a song. In our fourth session, Musa got the last laugh when she changed the ending to our good-bye song. We were singing "Goodnight Ladies". Musa looked straight at the young lady operating the video camera, opened her eyes really wide, and sang: "O'er the Deep Blue Seeewewewe." Then she commented, "She thinks I'm cute."

Musa enjoyed adding an echo, or call and response, to popular songs. For example Doris and I sang "K-K-K-Katie, Beautiful Lady, You're the Only G-G-G-Girl That I Adore," and Musa added, "That I Adore." She also created a new ending for Alice Blue Gown. We all sang the ending "My Sweet Little Alice Blue Gown," and Musa added her own ending, "Glump, Glump." I often extended these improvisations by engaging in a reciprocal call and response, tapping a rhythm on my guitar, and waiting for Musa to respond by tapping her own rhythm, or singing a musical phrase and waiting for Musa to echo or modify the phrase. This improvisation was extended to create a musical dialogue.

Redirecting Agitation

In our sixth session, we were able to use Musa’s creativity and playfulness to redirect her when she
became agitated. We were singing "She'll Be Coming Around the Mountain" and Musa became concerned about that old red rooster. Musa stated:

I was also insulted about the old red rooster part. I was furious. Anybody kills my old red rooster, I'm going to have a murder in my house.

She became increasingly agitated, scowling and raising her voice. She accused her great-grandson of stealing the chickens, "Every time it appears they're going to have chicken for dinner the chickens disappear!"

I improvised a new version of this song which reflected Musa's concern (And they stole the old red rooster from the chicken coop) and we all ended up laughing. Musa responded, "There you are. Makes me want to cry." We continued with another verse, "They stole the old red rooster and it makes me want to cry." Musa continued stating, "They really didn't kill him" which led to our next two verses:

They really didn't kill him, Oh no.
They really didn't kill him, Oh no, Oh no (repeat)

And if anyone kills my rooster, I'll get them, oh no.
And if anyone kills my rooster, I'll get them, oh no.
If anyone kills my rooster, If anyone kills my rooster, They'll answer to me.

Musa responded by laughing and saying, "That's the story of my life. Just one sad experience after
another." Doris laughed and reflected, "Just one sad story after another, that’s right," which led into our next verse:

That’s the story of my life
The sad, sad story of my life
That’s the story, That’s the story
The sad, sad story of my life.

Musa brought our improvisation to a close stating, "You’ve talked chicken and dumplings until I’m hungry. Are you two going to feed me or was I supposed to have brought...(her sentence trails off)." We ended this sequence with the traditional verse, "We’ll Have Chicken and Dumplings When She Comes."

We created a unique version of "She’ll Be Coming Around the Mountain." There were times during the song that Musa became disoriented and started fabricating stories about past events. At one point she became angry as she accused her great-grandson of stealing the chickens. In her perception these events were happening in the present.

Doris was familiar with the type of behavior that Musa demonstrated in this sequence. Musa often remembered something that happened in the past and responded emotionally as though the event occurred recently. In the sequence above Musa became distraught and was genuinely angry because she believed the chickens were stolen. Through the music, we were able to modify Musa’s mood and create an atmosphere in which
we all laughed and enjoyed Musa's creative imagination. We were able to turn a potentially uncomfortable exchange into a playful and humorous interaction.

Fostering a Sense of Collaboration

In our twenty-second session, Musa spent the entire session trying to remember the words to a song. She took the lead in initiating much of what happened in this session. The nursing staff reported there was a song that Musa sang that no one seemed to recognize. I was not familiar with this song either, but it had significance for Musa and she kept returning to this song throughout the session, trying to remember the words. We made up our own version of the song. The following sequence further illustrates Musa's creativity and sense of humor. Musa began the session, stating:

Yes. I was wondering. Among the branches where the white rush grow. I wish I could remember those old songs. Doris stated, "I do too."

Musa continued: "Down among the donkey where the hot branch grows. Lived a mighty warrior with the biggest of toes. Or something like that."

Doris and I both laughed, "I don't know that. Do you?" "Neither do I." Musa continued: "Anyway he got sick and whoop! And whoop came the browdry, and whoop came the briar man! And the last thing he brought was a launch, a merry launch diapese. That was a fine song. I ought to get that off some day."

I began to put a melody to the words that Musa was
reciting, singing, "Down among the branches," and Doris inserted, "Where the wild fern grows," adding to the song that we were composing. I continued singing:

Down among the branches where the wild fern grows
There was a little lady with the brightest of toes
She loves to dance, and she loves to sing,
And this is all of this song that we can sing.

Musa responded enthusiastically, "Sing that old song!" and added the next phrase, "Something came a clamping through the wilderness." I continued with the same melody, "Loud as it could be, and it made a ..."

Doris contributed, "It made a swish!" We were all three involved in this collaboration, making up a song around the lyrics and melody that Musa gave us.

She then returned to the song that she was trying to remember and recited the following verse, followed by a chorus which she sang a capella:

Down by the shane grate, close by the mill
There I met a yellow gal, her name was Nancy Field
She knewed that I loved her, she knewed it very long
While I’d serenade her, and this would be my song

Won’t you come along, come, come along with me
I’ll take you down to Tennessee
Won’t you come along, come, While the band has...hoie.. or something
And we’ll fly high and dry, on the ole banjo.

Musa concluded saying, "That’s one of my favorites." Doris commented, "I like that, but I don’t know it." Musa replied, "You mean I let you grow up without knowing that song?"

There was a sense of collaboration in this session
as we all contributed to creating a song. Musa initiated this improvisation, and kept going back to the task of remembering the words throughout the session. There were moments when Musa philosophized about the nature of life and aging, and later in that same session recited a poem. It was a poignant moment, as the poem reflected her movement through old age:

And the time grew, And the people grew
And the old songs sailed away
And the time grew, and the people grew
And more became less each day
And the time grew out, and the people grew out
Like the people who moved away.

Musa initiated most of the action in this session. She lives in a world in which she initiates very little. She spends most of her day sitting slumped in her wheelchair, not initiating interaction with staff or peers. She does not initiate even her own dressing, bathing, or grooming. She was once a woman who loved to tell stories and had a gift for describing events in a way that was quite eloquent. In this session she was on center stage. She interacted in a collaborative way, improvising words to a new song. She sang, she laughed, and she was completely wrapped up in the creative act of making music. She forgot, for the time, the pain and isolation which made up such a great part of her life.
Summary

Eventually the progressive nature of this disease made it more and more difficult to reach Musa. For a long period of time, over a year and a half, as we engaged in weekly music therapy sessions, familiar songs provided an avenue through which we were able to communicate with Musa. Her eyes lit up, and she actively joined in singing when songs from the 1930s or songs that are a part of her religious heritage were presented. Eventually, as the disease progressed, her responses became less consistent. There were times in which Musa was agitated and in pain, and not even the music reached her. Her ability to take an active and creative role decreased. Over a period of several weeks we had moments when Musa responded, but for the most part she was agitated, complained of pain, and repeatedly stated that she wished she could die. We decided at this point to discontinue the weekly individual music therapy sessions. Musa continued to receive music therapy in a group setting on her unit.

Musa and Doris participated in music therapy sessions over a period of eighteen months. Musa had already lost much of her capacity for relating to others, and yet her sense of humor shone forth. We collaborated and engaged in creative and playful musical improvisation. We laughed. We had fun. We

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shared feelings. Through the music we were able to contact that part of Musa which was light-hearted, humorous, creative, and bubbly.
CHAPTER V

HONORING THE LOVED ONE WITH DEMENTIA AND EMPOWERING THE FAMILY CAREGIVER

In reviewing the data collected in this study I began to look at the process through which music therapy contributes to quality of life. I summarized interventions utilized with the family caregiver and loved one with dementia. I then looked for ways to describe my approach to working with primary caregivers and their loved ones with dementia. I found my clinical approach could be summarized by the following statement: Music therapy honors the loved one with dementia and empowers the family caregiver.

I engaged first in an introspective search to find terms to describe what I saw happening in the music therapy sessions. The terms honoring and empowering summarized my intent in working with families. I reviewed video tapes, transcriptions, and logs, to search for moments in which music was used to honor the loved one with dementia and empower the family caregiver. The following criteria was identified. The process of honoring occurred (a) when the music therapist and/or caregiver listened to the loved one with dementia, (b) when the music therapist used eye
contact, gentle touch, and the unique qualities of music to bring the loved one into an awareness of her surroundings and what was happening in the present, (c) when music was chosen that was meaningful to the loved one because of past associations, (d) when the loved one was supported in verbally expressing feelings, thoughts, and associations elicited by music, (e) when the loved one was encouraged to express herself directly through music, by singing, composing and improvising lyrics, or exploring musical instruments, (f) when music was used to facilitate creativity, humor and playfulness, and (g) when music was used to soothe and comfort the loved one.

Family caregivers were empowered in moments (a) when tender emotions were shared, (b) when physical touch was used to express affection, (c) when they witnessed their loved ones actively engaged in expressing themselves through music, (d) when they took an active role in choosing music and meeting their loved ones needs on a moment-to-moment basis, (e) when they were able to soothe and comfort their loved one, and (f) when memories of past experiences and events with their loved one were stimulated by association through music.
The Honoring Process

Honoring the loved one with dementia is a process that occurs as the music therapist, family caregiver, and the loved one with dementia engage in music therapy. Webster’s dictionary (1970) defines honor as "to show great respect or high regard for" (p.64). The concept of honoring your father and mother is found in biblical scriptures Exodus 20:12 (Revised Standard Edition). But how do you honor your parent when communication and meaningful interaction is limited or non-existent?

The term honor is closely related to wording which defines patient’s rights. Federal law mandates that each patient be treated with "dignity and respect in full recognition of his or her individuality" (Federal Register, 1991, p. 48871).

Honoring is a concept that has been used in play therapy with children. Norton & Norton (1997) state that by listening and respecting the child’s expression of herself, the therapist communicates to the child that she is "valuable, honored and respected" (p. 17).

Honoring implies creating an environment in which loved ones with dementia are able to connect with the family caregiver and with that part of themselves that is central and healthy in their personality. Honoring implies setting aside time to be with the loved one

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with dementia. It implies nurturing musical responses, encouraging and facilitating the loved ones' efforts to express themselves. Honoring implies listening, receiving, and valuing what loved ones with dementia have to say, both in conversation, and through their music.

The progression of Alzheimer's Disease and related dementias slowly impairs the individual's ability to relate to others and to engage in meaningful pursuits. Doris describes this in her mother, stating that she "is just fading away." Ruth Bright (1988) interviewed a gentleman who stated that dementia is "like being in a fog" (p. vii). As this cognitive disease progresses, the individual loses the ability to communicate with others in a meaningful way. There is a sense of confusion, disorientation, and agitation as the individual is unable to communicate.

Moustakas (1975) in his work with children describes what happens when individuals feel that no one listens or understands what they are trying to say:

Repeated failure to communicate effectively one's own feelings, preferences, desires, and thoughts inevitably leads to painful frustration and doubts about one's value as a person. Ultimately, a profoundly diminishing sense of self is experienced (p. 1).

In addition to the cognitive decline that takes place, the loved one with dementia encounters social isolation as she becomes less and less able to
communicate with significant others. This inability to be heard, to communicate, and to connect with others leads to the erosion of one's sense of self. Those competencies and unique characteristics which make up an individual's personality begin to fade. The loved one with dementia becomes more isolated, vague, and withdrawn. Moustakas emphasizes the life-giving nourishment that being heard, received, and affirmed provides. "At any age to be heard in the way in which one is presenting oneself is a rich, human experience" (p. 3).

Honoring loved ones with dementia through music allows them to be heard and valued as unique individuals. Music provides the context through which thoughts, feelings, preferences, and desires are shared. What they have to say, and who they are, is received, recognized, and affirmed.

Validation is a concept that is similar to the honoring process. Naomi Feil (1982) developed a method of understanding the "disoriented old-old". She presents a model for understanding the life stages with which individuals struggle as they live to be eighty to one-hundred years old. She states they must "tie up living to prepare for dying. They restore the past to make closure and to justify their lives" (p. 1).

She describes the phenomenon I observed in music
therapy sessions. Both Mary Jo and Musa brought in material from the past. They experienced events as though they were happening in the present. These flashbacks were accompanied by emotions as though they were re-experiencing a traumatic event from their past. Feil states "Early-learned emotional memories replace intellectual thinking in the disoriented old-old" (p. 1). As cognitive disorientation progresses the old-old choose to retreat from painful present reality. They recreate the past to substitute for an unbearable present. Feil states disoriented old-old return to the past to:

- Re-solve unfinished conflicts by expressing feelings hidden in youth.
- Re-live past pleasures; re-place intellect with feeling.
- Re-stimulate sensory memories, to re-lieve boredom and stress.
- Re-treat from painful feelings of uselessness and aloneness (p. 5).

Feil emphasizes the importance of using empathy to tune into the universal feelings of the disoriented old-old. The helping role she describes is very similar to what happens when one utilizes a process-oriented approach in music therapy. She suggests that validation workers "tune into feelings, pick up rhythms; listen to verbal clues; observe non-verbal clues; put the feelings of disoriented old-old into words to give dignity, validating them" (p. 3). She emphasizes the effectiveness of using genuine touch, a
nurturing, caring voice, eye-contact and empathy. From the moment I pull my chair close to Musa’s, take her hand in mine, establish eye contact, and introduce myself, I am using "genuine touch, a nurturing caring voice, eye-contact, and empathy" (p. 11). Music has inherent qualities that make it an effective modality for tuning into feelings and providing a means of expressing these feelings. As Musa became agitated about who killed that old red rooster, I tuned into her feelings, picked up her rhythms, listened to verbal cues, and put her feelings into music. Musa moved from a state of agitation to a state of dignity and validation.

Feil provides a context in which we can empathize with the emotional distress and disorientation that persons with dementia present. She states there is intuitive wisdom in their retreat from present reality. Their task is to resolve past conflicts. Physical changes lead to loss of vision, hearing, awareness, and self-control. Images and feelings from the past replace the present. Memories and rhythms from early childhood survive.

Strong feelings remembered from childhood become our emotions. The inner sight, inner sounds, and smells of the distant past that evoke strong feelings are imprinted in our body/mind. These emotional memories are the "tapes" we play throughout our lifetime (p. 17).

Music taps into these early emotional memories,
and allows us to empathize, connect, and communicate with the loved one with dementia. Among these early emotional memory tapes are the lullabies our mother sang to us, the spiritual songs we sang in church, and the love songs we listened to in our youth. Feil suggests that we tap into the universal feelings expressed by the old-old, stating "the disoriented old-old person returns to Universal Feelings that all human beings share: love, hate, fear of separation, struggle for identity" (p.34-35). She refers to Jung, stating that universal feelings are the heart of fairy tales, classics, folk tales, and myths (von Franz-Hillman, 1971). As cognitive disorientation progresses these feelings are expressed without words. Symbols and body movements are used to communicate universal feelings:

Rhythms and rhymes come without reason, simply for pleasure, to avoid boredom: Sucking, humming, tapping, touching, trigger early memories. A rocking movement triggers an old "tape" a memory of rocking one's baby. The disoriented old-old woman rocks, pats her hand, moving backward in time to when she felt useful and needed as a mother. Her hand has become her baby. Early memories last the longest. The familiar movements play a familiar time of life (p. 35).

By picking up the movement, joining her rocking with a lullaby that validates the feelings behind her repetitive movement, we are able to join in her world, to validate, or honor, her need to comfort and be comforted. A connection is made, and the loved one is able to move from her solitary immersion in the past to
awareness and reciprocal interaction in the present.

Music has been called the language of the emotions (Noy, 1967). In a review of the psychodynamic meaning of music, Noy states that many authors refer to music as a symbolic language. As cognitive deterioration progresses, the disoriented old-old rely less and less on words and concepts to communicate. The words they use have little rational meaning, yet they communicate universal feelings and make symbolic reference to the past.

The music therapist also speaks with a language which conveys emotion and utilizes symbolic forms of expression. Music therapy taps into feelings the person with dementia experiences and expresses these feelings. Music can evoke and reflect universal feelings without the need for words. Through symbolic expression, music reaches a depth of feeling that words can no longer reach.

I am frequently surprised by the level of connection and communication that is achieved as I engage in music making with the loved one, and how quickly this connection disappears when the music stops and we attempt to communicate with verbal language. The loved one with dementia and the music therapist communicate on an emotional level through the symbolic language of music.
Empowering the Family Caregiver

The concept of honoring the loved one with dementia and empowering the family caregiver provides an overall framework for working with families. Music therapy empowers the family caregiver. Where there is a sense of helplessness, music is something that caregivers can still share with their loved ones. "Empowerment" is a term that has been used in social work, counseling, psychotherapy, and education. McWhirter (1977) emphasizes the role of collaboration in facilitating empowerment:

Collaboration refers to the dynamic relationship between the counselor and the client in which both are expected to play an active role. The relationship should be characterized by collaborative definition of the problem and collaborative development of interventions and strategies for change (p. 5).

In these sessions, family caregivers became co-facilitators, choosing songs that matched the mood and energy level of their loved ones, bringing in song materials that were part of their family heritage, providing physical assistance, encouragement, and praise for their loved ones. Sessions were structured to encourage family caregivers to take an active role.

Music therapy empowers the family caregivers and provides a means through which they can honor their loved ones. Doris commented that there are so few things she can do for her mother, the gifts she brings
on holidays and birthdays do not have any meaning for Musa. Music therapy is something she can give her mother which is still meaningful and is something that her mother can still enjoy.

**Clinical Application**

The concept of honoring the loved one with dementia and empowering the family caregiver provides underlying principles for working with families. Songs, instruments, and reminiscence are used to facilitate this process. The intent of honoring the loved one with dementia and empowering the family caregiver affects the way interventions are carried out within the music therapy session.

**Working With The Familiar**

Much of my work with families involved the use of familiar songs. Songs are heard by the fetus in a mother's womb from the sixth month of gestation. Songs are used as lullabies as a mother rocks her infant. Songs are used to promote the development of reciprocal movement and communication. Even before children learn to speak, they engage in rhythmic activities such as peek-a-boo, pat-a-cake, and are entertained with nursery rhymes set to music. Songs are an integral part of all the major social events in our lives, in
our religious ceremonies, birthdays, holidays, and patriotic events (Hodges & Haack, 1996).

Bright (1988) states that with music we are using old, well-established memory traces. The elderly respond to songs they are familiar with, songs heard in childhood and early adult years, and songs associated with religious services. By honoring their preferences and joining them in the music of their heritage, we acknowledge and value the life they lived, and, therefore, acknowledge and value them as unique individuals.

For the music therapist this means that the same songs may be repeated in every session. Each session with Musa was opened with the song "K-K-K-Katie," a World War I song, as she invariably became actively involved and engaged when this song was presented.

There is always a balance to be kept between repetition and the presentation of novelty. Novelty is an essential ingredient not only because it provides cognitive stimulation for the loved one with dementia, but because it keeps both the family caregiver and the music therapist engaged and motivated.

Addressing Emotional Issues and Needs

Songs are chosen not only based on the loved one with dementia’s background and preferences, but also to
address emotional issues and needs as they arise. The decision of what song to choose often relates to mood and energy level. The bubbly, creative side of Musa was accessed through energetic songs with humorous themes and fast tempos, while songs that were soothing and comforting were chosen to decrease agitation or provide relief from physical pain.

Setting Aside Expectations

Expectations are set aside as needs may vary greatly from one session to another. One week the loved one may be alert, active, and engage in creative and energetic music, and the next week she may be in pain and unable to tolerate more than a brief period of music.

In session number twenty-three, with Doris and Musa, I brought an omni-chord and rhythm instruments. The week before Musa was active and played the metal xylophone, the omni-chord, and the paddle drums. I was prepared to continue the kind of musical improvisation that we engaged in previously. This week Musa’s energy level and her needs were completely different. We tried the omni-chord and the maracas but Musa did not have the energy to play for a sustained period of time. We adjusted our pace to match hers by singing "Amazing Grace" and "Kum-Ba-Ya". As we gently rubbed her back
we connected with Musa. We matched her energy level and met her need in that moment.

**Taking Cues From the Loved One**

The process of honoring implies taking cues from the loved one with dementia and structuring the session to meet the needs presented. Whether it is the introduction of a new instrument to explore, a rousing chorus of a familiar song, or the spiritual comfort of a slow gospel song, music is chosen to facilitate meaningful interaction with the loved one on a moment-to-moment basis. This requires an attitude from the music therapist of being responsive to emotional needs presented, and a willingness to be creative and innovative in meeting and interacting with the loved one through music.

**Being Present and Responsive**

In honoring the loved one with dementia, and being present and responsive with music, we are receiving, valuing, and affirming the individual. The loved one perceives that she is received and valued, and she connects with a sense of self. A level of participation, creativity, and self-expression is accessed that is not seen in other settings.

In session number seven, I found Mary Jo sitting
in the dayroom attending a worship service. She did not join in singing in the group setting, however, as we began our session with some of the same hymns she sang with assurance and enthusiasm. We finished singing and Mary Jo stated, "That was pretty. I sure thank you."

The conversation turned to how people get too busy and do not take the time to sing or play even if they like music. I made the comment, "nowadays people do get too busy," and Mary Jo added, "And overlook things that really are important, and would be helpful to them; things like this." As we closed our session she made the statement, "Thank-you for doing this for me cause it really helps."

In session number six we sang a back rub song in which all the participants share a back rub. Mary Jo smiled and laughed, and said, "You can come back and do this anytime." The music provided an opportunity for Mary Jo to have meaningful interaction with her daughter and to connect with that part of herself that was still joyful and healthy.

Utilizing Creativity and Spontaneity

Creating new lyrics to a familiar song or composing a song provides another vehicle for facilitating interaction, and for meeting a wide range
of needs that spontaneously emerge within sessions. This ranges from simple variations on familiar songs, such as when Musa added her own ending to songs we were singing, to word substitutions as we improvised verses to familiar songs. Word substitution often takes the form of humorous interplay between the loved one with dementia, the family caregiver, and the music therapist.

Songs and improvisation of song material provided a means of reducing agitated and restless behavior. When Mary Jo paced, I improvised a walking song that allowed her to stay connected with us even as she was walking around the room. The music provided a socially acceptable framework for her pacing. She was able to return spontaneously to her seat and her interaction was more relaxed and focused. In session number six, Musa became quite distraught over the idea that someone killed the old red rooster. We were able to redirect her by improvising numerous verses based on "She’ll Be Coming Around the Mountain." In session number two, Mary Jo became very concerned and agitated over the production of a play. Her feelings were quite intense as she replayed this traumatic event from her past. We were able to redirect and comfort Mary Jo by singing a quiet, soothing song as she sat passively and relaxed.

There were moments in which word substitution
provided an opportunity for the loved one with dementia to communicate something that was touching and meaningful. Words are improvised to give voice to the feelings, conflicts, desires, and concerns the loved one brings with them to the music therapy session. This was illustrated in the session when Mary Jo stated that all she would ask God for was her health and her family. Providing these few words within the context of the familiar song, "Kum-Ba-Ya," communicated clearly what she still held to be the most important factors in her life at that point in time. On another occasion, Musa spontaneously recited the words of a touching poem reflecting movement through old age.

And the time grew, And the people grew,
And the old songs sailed away

These are eloquent and descriptive words spoken by a woman who had difficulty completing even one sentence. Within the context of the music therapy session she was able to capture her experience of aging through prose.

Honoring The Sound of The Loved One

The use of musical instruments also plays an important role in my work with families. I utilized an improvisatory approach in which I allowed the loved one with dementia to explore the sound of the instrument. The family caregiver took a supportive role, either listening and honoring the sound of their loved one as
they explored the xylophone, assisting by holding a drum, or encouraging their loved one with praise and verbal cues. I provided support in the form of accompaniment to their improvisation.

In using instruments, I was interested in facilitating creative exploration and discovering another way to communicate. I let the loved one take the lead in exploring the sound of the xylophone and chime bars. I listened, provided encouragement, and found ways to join with the music created by the loved one with dementia.

Clair & Bernstein (1990) found that as dementia progresses, individuals tend to respond more to use of instruments rather than song. In my work with Mary Jo and Musa I found instruments provided a sense of novelty. I did not find them to be a preferred modality because of the more complex motor skills that are involved in playing instruments. The use of instruments involves fine motor and eye-hand coordination. It involves using objects functionally. Each of these skills requires a higher level of cognitive functioning than singing or simply listening to music and responding with eye contact and facial expression.

I often chose to use instruments at times when the loved one with dementia was exhibiting a high level of
energy and seemed to be more oriented than usual, up for a challenge. In session number twenty-two, Musa spent thirty minutes exploring different instruments. She played a melody on the xylophone, which we were able to pick up on and sing with her, she strummed the plate on the omnichord as we sang several of her favorite songs, and played the paddle drum as accompaniment to a marching song.

It was an unusual experience to see her so invested in an activity. She was completely focused and exhibited no sign of agitation or disorientation throughout an entire thirty minute period of music making. She was using objects functionally. This is a woman who had lost the ability to perform even the most basic self-help and yet she was able to utilize these instruments in a functional way. Musa played the piano in an earlier time, and she enjoyed the opportunity to once again make music in a creative manner.

Honoring the sound of the loved one as they play an instrument validates that person. I found that Musa and Mary Jo often became totally absorbed in the act of exploring the sound of an instrument. There were so few contexts in which they could create and be acknowledged for having produced something meaningful. By listening and supporting this sound we acknowledged that the sound they produced had value and meaning,
their music, who they are as a person, had value and meaning.

Instruments provided the family caregiver with an opportunity to take an active role in the session. Both Connie and Doris experienced a sense of pride as they supported and encouraged their mothers' instrumental improvisation. Finding an activity that they could still share was empowering.

**Facilitating Associations With the Past**

Reminiscence is an important developmental task for the elderly (Butler, 1963). It helps one to integrate and make sense out of the events of one's life. An individual can look back over his life, see that it was productive, recall the positive experiences, and reconcile the negative experiences (Erikson, 1985). The ability to reminisce is impaired by difficulties inherent in word retrieval. Music provides a format through which these memories can be accessed.

Sandmaier (1998) states that caregiving is about "reengaging with the most profound and influential attachment of our lives" (p. 24). Utilizing music to stimulate reminiscence provides an opportunity for life review both for the loved one with dementia and the family caregiver. The loved one with dementia is
honored as memories of significant events and relationships are acknowledged. The family caregiver is empowered as she reviews the unique heritage that her mother passes to her and experiences once again the significance of this relationship.

Both Mary Jo and Musa shared a rich heritage with their daughters. At one time Musa was able to tell elaborate stories about her family history. Occasionally a song would evoke a memory that Doris shared with Musa, such as when we sang "Sidewalks of New York" and Doris reminisced about the plays that she and her mother saw in New York City. Another time we sang "Somewhere Over the Rainbow" and Doris reminded Musa of a time when she took her granddaughters to see the Wizard of Oz. They were so scared when the flying monkeys came out that they jumped in Musa’s lap and cried. This led to the acknowledgement that the grandchildren had shared a lot of good times with Musa and her husband. Even though Musa did not remember this event, or could not put it into words, she did remember the feeling of closeness that she had with her grandchildren as they were growing. Musa reminisced:

They were two funny little kids. I commented, "They had a lot of good times with their Grandmother, didn’t they?" Doris replied, "Oh sure they did. They loved their Grandmother and Daddy Pop." Musa concluded, "Well, it was a great life!"

Finding the words to describe a memory was
frustrating for Musa, and it took effort on the part of Doris and myself to follow what Musa was saying. The music provided a framework. We could engage in verbal conversation and reminiscence, and when this got tiring or frustrating we could break it up by singing a song. The singing was energizing and allowed us to sustain and enjoy this interaction.

Musa was able to connect with positive memories of times spent with her grandchildren as they were growing up. Recapturing positive feelings about one's life is what makes reminiscence a valuable experience. Reminiscence allows elderly persons to look back over their life with renewed hope and to recognize their life as having been worthwhile.

Reminiscence allowed the daughters in this study to review past experiences that they shared with their mothers. As part of the grieving process, family members often seek out information about their heritage (Hargrave & Anderson, 1992). The memories stimulated by music allowed Connie and Doris to review the positive memories they shared with their mothers and to preserve memories related to their family legacies.
CHAPTER VII
BENEFITS OF MUSIC THERAPY

In describing the relationship with their loved one, the participants in this study report a sense of grief and loss, isolation and loneliness. Music therapy cannot take away the loss and grief associated with caring for a loved one with dementia. It cannot reverse the progression of Alzheimer's Disease. Music therapy does provide a source of support for the family. By offering opportunities for meaningful interaction during the final stages of this terminal disease, the quality of life for both the family caregiver and the loved one with dementia is improved.

Sessions were videotaped and transcribed. As I reviewed these transcriptions I made notes in the margin, identifying problems and ways in which music was used to facilitate communication between the family caregiver and the loved one with dementia. These notes were then reviewed and organized into categories describing qualities of music that facilitated communication and enhanced quality of life.

Benefits of music therapy can be discussed from three points of view: (1) the loved one with dementia,
(2) the family caregiver, and (3) the relationship between the loved one with dementia and the family caregiver.

Benefits for the Loved One With Dementia

Music Bypasses Sensory and Auditory Processing Obstacles

Musa has a visual and hearing loss. She appears to be deaf when you talk to her. If you make a verbal statement she will ask you to repeat it, or she will respond with something which is loosely related to what was said. She is unable to process verbal language, and yet she hears and processes music. Her interaction becomes fluid and spontaneous when we are engaged in singing or in improvising lyrics to songs.

Individuals with Alzheimer’s Disease may retain the ability to process music when they have difficulty processing language (Erdenmez, 1993; Braben, 1992). The exact psychophysiological process that allows this phenomenon to occur has not been clearly defined (Thaut, 1990). In a review of the literature, Brotons, Kroger, & Picketts-Cooper (1997) conclude:

research suggests that music processing which is preserved in ADRD may be occurring in different parts of the brain than familiar linguistic mechanisms. Further, these regions may be the last to deteriorate in the disease process, at least in a subset of ADRD patients. Because the creative arts therapies in general, and music therapy specifically, rely less on verbal processing, they may offer a unique approach to
accessing stored knowledge and memories that control certain behaviors (p.211).

This was demonstrated in our first session with Musa. Doris reported that Musa used to play Alice Blue Gown on the piano. I suggested that we sing this song as it had associations with the past for Musa. Doris and I had difficulty remembering the words, but Musa remembered them and sang all the way through.

Doris commented, "You remembered a lot of that one. You remembered more than we do." Musa replied, "Oh that is just a branch of intelligence that starts from a clear corner. I didn’t even tell you about it."

Although Musa had difficulty putting it into words, she seemed to be confirming that music was something she had no difficulty understanding. Erndomez (1993) describes a woman who is unable to respond with her name, and does not know what day it is, but joins in singing a familiar song, recalling both the melody and lyrics. Short term memory storage is severely impaired in people with Alzheimer’s Disease; however, recall of material in long term memory, information originally laid down by rote learning, is well preserved.

Music Provides Moments of Connection With the Present

Individuals with dementia live in a world where memory is distorted. Events of the past are experienced as though they were happening in the
present. Music brings the person with dementia into an awareness of what is happening in the present. This occurred in session one when Mary Jo was sitting with her daughter. Her conversation was tangential and difficult to follow. As soon as I introduced myself and picked up my guitar, Mary Jo established eye contact and exchanged appropriate greetings. She became aware of what was happening in the present.

Musa can be observed in videotapes sitting in a wheelchair in a hallway or bedroom, not initiating interaction with staff or peers. Yet within music her interactions are spontaneous and meaningful. Theories of emotion and arousal (Myer, 1956; Mandler, 1984; Berlyne, 1971) suggest that music provides an element of novelty that results in an alerting of the autonomic nervous system. Thus, even in the presence of cognitive degeneration, music elicits responses within the limbic system, engaging the thalamic, hypothalamic, and brain stem areas (Erdonmez 1993). Clair (1996) states music provides structure and predictability through rhythm, form, and familiarity. These musical elements facilitate mental organization and allow individuals with dementia to respond meaningfully to sensory stimulation (Thaut, 1990).
Music Facilitates Expression of Tender Emotions

The family caregivers with whom I worked have a great deal of love and regard for their mothers. Connie describes her mother as someone who was a source of nurturing. Mary Jo is no longer able to fill this role for her daughter. Music allowed Connie and Mary Jo to connect on an emotional level. It facilitated the expression of tender emotions. As we sang "Kum-Ba-Ya" in our second session, and Connie asked what she would ask for, Mary Jo was able to tell Connie that family was still the most important thing to her. Even at times when Mary Jo was passive, we were able to surround her with an envelope of soothing, comforting music.

Both music and emotions are mediated by brain structures in the thalamic, hypothalamic, and brain stem areas. This is one explanation for the fact that music can easily access and modify emotional states. Thaut (1990) suggests that music therapy can be a powerful tool for impacting affective behavior processes. He suggests that music therapy techniques are used to facilitate the experience, identification, expression, and understanding of emotion. Individuals with dementia are lacking in each of these areas. The ability to identify, modulate, and communicate emotional experiences is an important factor in healthy
ego function and social interaction.

The loved one who sits with her head down, unaware of her surroundings, who seems so far away that she cannot be reached is no longer in touch with any kind of emotional experience. With the introduction of music, she is put in touch with that part of herself that makes her human, music evokes emotional response.

In another scenario, the loved one with dementia is talking, but there is no communication. There is a sense of isolation on the part of both the family caregiver and the loved one. Music facilitates expression of emotions, and understanding of emotional communication of others. A bridge is formed between the family caregiver and the loved one. For a brief period of time they can relate to one another as mother and daughter.

**Music Reduces Agitation**

In session twenty-one Musa became agitated and started accusing someone of killing her rooster. We were able to redirect her by engaging in songwriting and turning her potentially catastrophic reaction into a humorous exchange. In the first session with Connie we were able to use the soothing quality of a spiritual folk song to calm her.

The use of music to reduce agitation is confirmed
by Brotons & Pickett-Cooper (1996) who found that patients were less agitated during and after music activities which included singing, playing instruments, dancing/moving to music, composition/improvisation, and games. These results are further supported in research conducted by Bright (1986), and Groene (1993).

Clair (1996) and Fitzgerald-Cloutier (1993) describe techniques to decrease agitation and engage musically with patients who are wandering or pacing. Clair suggests that the caregiver initially utilize music that matches the loved one’s pacing in tempo and volume, singing and moving with the loved one. Then as the music elicits response, the tempo and volume can be decreased until the loved one relaxes and it is possible to direct him or her to another activity.

Music Reduces Pain

The effectiveness of music in reducing pain has been demonstrated in a variety of medical settings (Standley, 1986; 1992). It is distressing to be the caregiver when a loved one is in pain and there is nothing that seemingly can be done to alleviate the pain.

In session eight Musa kept saying over and over, “I’m so tired, I’m so tired.” She was not her typical alert self, she was bent over with her head down.
Doris encouraged her to come to music, hoping that it would make her feel better.

Musa was in distress and began to cry. Her voice was tense and strained as she cried out, "I don’t want to go to jail!". Doris reassured her, holding and massaging her hand. Musa asked, "Where’s your home? Where do you live?". Then she said "I guess they can push me in the river, find a river".

I joined Doris in rubbing Musa’s knees and sang "Alleluia", a song that reflected our movements as we massaged her knees and back. Musa cried out, "I’m so tired, I don’t want to be tired!". Doris encouraged Musa, "Let’s just listen to the music for a few minutes, then we’ll go".

I sang "Kum-Ba-Ya." As I sang, "Give me peace", Musa cried, "I’ve been hunting you. Thought you’d gone off and left me". I continued with "Someone’s Praying Lord." Musa said, "I feel better," and as I sang, "Someone’s singing Lord", Musa’s face relaxed, her body posture softened, and her breathing slowed.

Musa sat with her head down and eyes closed, and reflected on some past disappointment, "wanted to come so bad but they just couldn’t. Have to work for a living." As we finished singing "Kum-Ba-Ya" Musa said, "That was pretty."

Musa continued to relax, her breathing even and slow as we sang "Amazing Grace." She was asleep as we ended the session.

Doris left the session with a feeling of gratitude as we were able to do something to ease her Mother’s pain.

There are several theories which explain the use of music to reduce pain. Clark, McCorkle & Williams (1981) in their work with music in childbirth relate music to gate control theory stating that music activates large nerve fibres which inhibit the
transmission of pain. Goldstein (1982) suggests that music stimulates the release of endorphins in the bloodstream. Clair (1996) states that music alters the perception of pain by providing distraction which distorts time and provides relief from boredom and inactivity.

Music Provides Opportunity For Creative Self-Expression

Creative self-expression is played out in our lives through the many roles that we take through our work, through our roles as wives and mothers, and through our interests, hobbies, and special projects. Connie described how, one by one, these things that were important to her mother were stripped away. She was no longer able to cook, to sew, to prepare care packages for her grandchildren, to care for her husband or for herself. Music therapy facilitates creative self-expression. The ability to be creative and expressive is not lost with Alzheimer’s Disease. Music therapy provides a vehicle through which creativity and self-expression can be accessed.

Examples of Musa’s creativity could be found in almost every session. She loved to change the endings to songs and engage in rhythmic dialogues. She engaged in extended improvisations in which we created new lyrics to familiar songs, and participated in musical
dialogues in which we exchanged melodic and rhythmic phrases. She was able to express a variety of emotions ranging from humor to anger and frustration, to loneliness and longing.

Every individual with dementia is unique, both in personality and in the extent and course of cognitive deterioration (Tomaino, 1998). Mary Jo was less spontaneous, but she had a deep love for music and consistently responded with positive comments when we sang familiar songs. She had always admired her sister’s ability to play the piano, and enjoyed exploring the sound of the xylophone.

Bright (1988) defines creativity as “exploration of oneself, one’s surroundings and one’s relationships; newness, even if this consists of rediscovery of forgotten joys (p. 43).”

Exploring new instruments, creating lyrics, engaging in rhythmic improvisation, moving to music, remembering past events and expressing feelings are avenues of self-expression that Musa and Mary Jo were able to access through music.

**Music Provides Opportunity For Goal-Directed Behavior and a Sense of Accomplishment**

The dementia patients in this study engaged in goal-directed behavior and experienced a sense of accomplishment with the music that they created. They
were able to use objects functionally when they played musical instruments. There was a sense of accomplishment on the part of the loved one with dementia and a sense of pride in the family caregiver as their loved one made music. There were several instances in which Musa made comments such as "We're pretty good," or "Bet you didn't know I could do that." Doris stated that she left the session, "floating on a cloud," when Musa was able to pick out a familiar melody on the xylophone. She knew that Musa had derived pleasure for many years playing the piano and she was overjoyed to see that she could still play a familiar melody.

Benefits For The Family Caregiver

Music Therapy Reduces the Sense of Helplessness

Music provides the caregivers with a tool and an avenue through which they can spend quality time with their loved ones. This is something they can do with their loved ones which is a positive experience. As daughters watch their mothers engage in music making, laughing and enjoying themselves, they discover something meaningful that they can share with their loved ones. It will not change the disease but it does reduce the sense of helplessness.

In an interview following our second session,
Doris stated that there were times when she visited Musa that she didn’t get any response at all, "she’s so far away I can’t reach her." We reviewed our experiences following our fifth session and Doris reported:

I have really looked forward to it. Because I feel like it’s something we can do together, and there are really so few things we can do together. It’s hard to carry on a conversation. I don’t always know where she is or about whom she is speaking, but I think, that in the music, that we really have found a bridge.

Music Provides an Additional Support Person for the Caregiver

As the series of music therapy session progresses, a relationship is forged between myself and the primary caregivers. Doris and Connie were not alone. I provided an additional support person who shared this journey.

Music Provides a Collection of Positive Memories

Many people do not have positive memories of the time spent with their loved one in a nursing home. Doris and Connie were given copies of videotapes of our sessions. On one occasion these videotapes were shared with the extended family as a gift at Christmas time. Not only did Doris and Connie engage in an activity which was enjoyable, they also received a taped record which documented their participation in this project.
and served as a family heirloom.

**Music Provides Opportunities For Positive Interaction During Extended Family Visits**

Holidays and birthdays are often times that extended family gather and visit their loved one at the nursing home. On one such occasion, Doris arranged a music therapy session with the extended family. There were four generations present: Musa, her daughter, Doris, two granddaughters, and five great-grandchildren. The same creativity and love of music that Musa demonstrated was present in her multi-generational family. We danced, we sang, we laughed, and at the end of the session the family had a videotape of the session. Doris’ daughters remembered many of the children’s songs that they learned at summer camps and were spontaneous and active, involving the great-grandchildren in movement and song. Quite often visits to grandmother or great-grandmother in the nursing home can be sad and disturbing. There is a sense of grief in seeing a loved one who no longer relates to you as they did when you were a child. This is such a contrast with the joy and laughter that was evident within this extended family music therapy session.
Enhancing the Relationship Between Family Caregiver and the Loved One with Dementia

Music Reduces Isolation and Loneliness

Isolation and loneliness are feelings that both the family caregiver and the loved one with dementia experience. As dementia progresses, the loved one becomes less able to interact in a spontaneous manner with the environment. They become increasingly isolated as they are no longer able to process and respond to what is happening around them. Gaston (1968) states "Music involves the individual so totally and in such unique fashion that closeness is felt, and painful aloneness is alleviated (p. 25)." The loved one with dementia moves from isolation to a sense of connection.

Family caregivers also experience isolation and loneliness. Quite often their lifestyle becomes more isolated as caregiving consumes time. Other significant relationships may be strained as time is devoted to the caregiving role. Throughout her life, a daughter turns to her mother for nurturing and support. With the progression of this disease, the person to whom she once turned for nurturing and support is no longer emotionally available. It is a frustrating experience for a daughter to visit her mother day after day, week after week, month after month, and year after year, when there is so little that she can actually
share with that person. She cannot share the events of her day with her mother as she once could. There are no more ‘heart to heart’ talks. Music allows the family caregiver and the loved one with dementia to spend time engaged in a positive activity. It facilitates those heart-to-heart connections between mother and daughter.

Music Provides Glimpses of Previous Level of Functioning And Former Personality

In her testimony at the 1991 Senate Hearing, Mrs. Lois Johnson testified: "The thrill of seeing a little glimpse of the Tom I used to know was overwhelming (Scovel & Wilson, 1992, p.47)." Bright (1988) states "for many families it is only through music that they see a (temporary) restoration of the person they once knew (p. 53)". She states:

It is the change from an active involved person to an apathetic one, that families find most distressing, so that to provide an environment in which the personality of the dementing person is restored, even if only for a few minutes, is a source of joy to the family (p. 54).

Tomaino (1998) found that despite cognitive deterioration personality remains in tact. I saw this over and over in the video tapes. There are moments when Mary Jo smiles and says the most gracious things about how glad she is to see me, and there are quite a few moments when Musa is indeed bubbly. In spite of
cognitive deterioration the unique characteristics which make up the personality of these women were still present.

Music Provides Opportunities for Humor

As I was reviewing and transcribing video tapes I was struck by the amount of laughter that I heard on the tapes. Laughter in itself is healing. Connie states, "you just have to keep a sense of humor about these things." Again I am struck by the nature of most visits with loved ones with dementia, and the spontaneity and humor with which our music therapy sessions were filled.

Music Provides Spiritual Inspiration

Spiritual songs are often chosen when there is a need for music that is soothing and calm. Religion has been an important part of the lives of many elderly persons, and, at this time, there is a tendency to draw upon religion as a source of comfort and hope. Songs that were sung in church are often remembered and cherished by the elderly. In singing these songs I am often struck by the direct correlation between the lyrics and the reality of this stage of life. Many of the messages of spiritual songs have to do with death and with the hope of life after death. Although never
formally acknowledged, I feel that it is appropriate to be singing and experiencing these songs, with their message of hope and inspiration, as the loved one with dementia draws closer to the moment of death and their caregivers prepare for this loss.

**Music Provides Opportunity for Physical Interaction and Affection**

In a support group in which we shared our research with other families, Connie stated that one of the most meaningful moments in our sessions was when her Mother spontaneously reached over and hugged her. This may be one of the things that she misses most about the relationship which she used to have with her Mother. In our initial interview Connie stated, "I used to go home to be nurtured and taken care of." With the role reversal and cognitive impairment there are few times when Mary Jo reaches out to express her affection in a spontaneous manner.

One of my favorite songs is one in which the participants engage in a backrub. During the music session there are opportunities to hold hands with a loved one, or to rub their knees or their back in a comforting manner. As Musa’s condition deteriorated there were sessions in which the music did not seem to touch the pain. When Musa moaned, crying out that she just wanted to die, Doris held her and hugged her,
telling her how much she loved her.

Summary

I began this study observing that some families continue to be involved with their loved ones while others become discouraged and visit less and less, or not at all. The benefits outlined above demonstrate ways in which music can be used in therapy to assist families in maintaining a relationship with their loved ones with dementia.
CHAPTER X

SUMMARY AND RECOMMENDATIONS

The qualitative method utilized in this study allowed me to take an in-depth look at my work with families. Music therapy has much to offer families with a loved one with dementia. Doris identified what I feel is the most important finding in this study, when she stated in a letter that music therapy allowed her to experience quality time with her Mother.

The saddest part of dealing with Mother is that the quality of our time has deteriorated so much. She asks the same question again and again in a short period of time. She rambles with no continuity of thought. She loves to talk and can be quite witty still, but after a while, she begins to have trouble forming her words and this is so frustrating for her. I often leave with a great sadness, remembering the wonderfully intelligent person she was. But on Thursday mornings when we meet and let music be a part of our lives, those feelings disappear. The singing and the activity of the hour have actually become a time of real quality. When I roll her out the door, I take her back with a peace in my heart. I am thankful for that blessing.

The concepts of honoring the loved one with dementia and empowering the family caregiver provide a framework for working with families and describing the dynamic relationship that develops between the family caregiver, the loved one with dementia, and the music
therapist. These guiding principles affect the way that familiar songs, songwriting, instrumental improvisation, and reminiscence are used within the session. Within the field of music therapy it is important than we look at the therapeutic process that contributes to the effectiveness of music therapy interventions with families.

There are thousands of caregivers who have taken the role of primary caregiver who have very few positive memories of the time spent during the terminal stages of this disease. Music therapy provides opportunities for family caregivers to connect with their loved ones on an emotional level, experiencing closeness, joy, spontaneity, and creativity.

Music therapy allows the person with dementia the opportunity to connect with their child. Music overcomes cognitive, sensory, and physical limitations. It eases pain, soothes, comforts, and allows the person with dementia to connect with the present, to tap into their own creativity, to engage in self-expression, to connect with healthier aspects of their past, and to share quality time with their loved ones.

The music therapist becomes a support person for the primary caregiver as they journey on this path. There was a bond and connection that was forged between the family caregiver and myself, as the music
therapist. We shared intimate moments and I witnessed the progression of this disease over the course of more than a year. Both Connie and Doris turned to me as a source of support as their mothers’ diseases progressed. I have been there with them, and yet have a distance from the process as I am not the primary caregiver, this is not my mother, and I do not see myself as responsible on a daily basis. In this role I have been able, on occasion, to be a source of comfort and assurance for them.

I intend to continue to follow Doris and Musa and Connie and Mary Jo through the terminal stages of this disease. The observations that I have recorded here captured interaction that occurred at a particular stage. Both patients with dementia were diagnosed with Alzheimer’s Disease and had been placed in a nursing home. As the disease progresses, the nature of their interaction will change. Documenting the changes in the nature of our music therapy session, and discovering ways to preserve quality of time spent together as this disease progresses is a project that is on-going.

As this study progressed, further questions emerged that could provide the basis for future research. The participants in this study consisted of mother-daughter relationships. Further research could
include husband and wife dyads, and explore differences in musical responses over a longer period of time as cognitive deterioration progresses. Responses to music are highly individualized. The responses described in this paper are particular to two mother-daughter dyads. There is need for additional documentation of the music therapy process in working with families.

Other target populations could include family members who have not maintained relationships with their loved ones because they find this relationship too distressing. I would like to see music therapy available to families who have recently placed their loved one in an institution as this is a particularly stressful time. This study was carried out with loved ones who had been placed in a nursing home setting. Many of the same issues are addressed when working with caregivers in the community. The research in these areas are complementary. I would hope that this study may inspire music therapists to work with individual families and to develop long-term supportive relationships with those who are courageous enough to take on the task of primary caregiver.

Music therapy has much to offer families with a loved one with dementia. This is information that a lot of families struggling with this disease do not have. Avenues for disseminating this information and
funding for music therapy for families need to be explored.

I would like to close by thanking the families who have shared their journey with me over the past year. I look forward to continuing this journey as I trace the use of music therapy throughout the progression of this disease.
BIBLIOGRAPHY


Bright, R. (1986). The use of music therapy and activities with demented patients who are deemed "difficult to manage." *Clinical Gerontologist, 6*(2), 131-144.


APPENDIX A

RELEASE FORMS

Human Rights Statement

Participants in this pilot study will consist of individuals with Alzheimer's Disease and one or more family members or significant others. These participants will be recruited from volunteers in the area of Amarillo, Texas. Participants may be referred by nursing home staff, or recruited through the Amarillo Chapter of the Alzheimer's Association.

Participants will take part in an individual interview and music session for the purpose of assessment. The identified family member(s) or significant other(s) will then participate in a series of six music therapy sessions with their loved one with dementia. These sessions will be approximately 30-60 minutes in length depending on patient's endurance and can take place once or twice per week.

The researcher will present the prospective family caregiver with the attached Statement to the Subjects and the consent form. Information will be reviewed with the legal guardian of the individual with dementia. The legal guardian will be asked to review this information with their family member with dementia, and to sign the consent form if they believe that participation in this study is in the best interest of their family member with dementia.

Data collected from audio and/or video tape and written transcriptions will be reported in the research document, however, names and all identifying characteristics will be changed to insure the participant's privacy. Video tape material may be used in the preparation of educational materials. Participants will be given opportunity to preview video and will sign additional release to use video for this purpose.

As stated in the consent form, participation in this study is voluntary and each subject has the right to withdraw at any time.

The music therapy intervention does not involve any health risks. There is no potential harm for those participating in this study.
STATEMENT TO RESEARCH PARTICIPANTS

In this pilot study, the principal investigator will be attempting to investigate the use of music therapy to enhance communication between individuals with Alzheimer’s Disease or related dementia and their families.

Participation in this study is voluntary and will not adversely affect the participant's rights and welfare. It will involve:

1. Participation in at least one individual interview and music session for the purpose of assessment.

2. Participation in a series of music therapy sessions to be held jointly with the individual with dementia and the family member(s) or significant other(s).

3. The sessions will be audio and/or video-taped. A written transcription of the sessions will be made. Participants may have a copy of the audio or videotape and the transcript if they so choose. In reporting data, names and all characteristics will be changed to insure participant's privacy.

4. Portions of the video tape may be used for educational purposes. Participants will be given an opportunity to preview any portions of the tape to be utilized in public or academic setting. Participants will sign release form before any material is used for this purpose.

5. Participants may withdraw from the study at any time and, if requested, the principal investigator will destroy the transcript, tapes, and logs. This music therapy intervention does not involve any health risks. There is no potential physical harm for those participating in this study.
FAMILY CONSENT FORM

CAROL GARDNER
6100 HATFIELD
AMARILLO, TX 79109
806-358-9017

I have agreed to participate in the study seeking to investigate the use of music to enhance communication between individuals with Alzheimer's Disease or related dementia and their family member or significant other and hereby give my consent to be a subject.

The principal investigator has explained that my participation in this study is voluntary and involves the following:

1. Participation in one individual interview and music session for the purpose of assessment, and a series of music therapy sessions to be held jointly with the individual with dementia and a family member or significant other.
2. These sessions will be audio and/or video taped. A written transcription will also be made. I may have a copy of the transcript and tapes if I choose. I am aware that anonymity is assured by changing names and characteristics of participants in the written research report. I understand that I will preview and sign a release form if any audio-or video-taped material is to be used for educational purposes.
3. I may choose to withdraw consent at any time. If I so choose, tapes, transcripts, and logs will be destroyed.
4. The principal investigator will review the clinical chart of the individual with dementia for pertinent information and consult with members of the health care team.
5. All tapes and transcripts will be kept by the principal investigator for further research purposes only, unless otherwise requested. I will receive feedback on the results of this research if I should so desire. I am free to contact the investigator should I have any questions about this study.

_________________________  ________________________  ____________________________
Subject's Signature        Date                  Subject's Name (Printed)

Carol Gardner MA RMT/BC   __________________
Date
MUSIC THERAPY RESEARCH PROJECT

ENHANCING COMMUNICATION BETWEEN FAMILY MEMBERS AND INDIVIDUALS WITH DEMENTIA

At least one of your resident families have expressed an interest in a study investigating the use of music therapy to enhance communication between dementia patients and their family members. This study will consist of the following:

1. An interview with the participating family member(s) for the purpose of introduction to the study and assessment.

2. An individual session with the dementia patient for the purpose of assessment.

3. Review of the resident's medical chart and consultation with the staff working with this resident.

4. A total of at least six sessions in which music is used in a joint session with the dementia patient and family.

5. Data will be collected by either audiotaping or videotaping sessions. Written transcriptions will be made from these tapes. The music therapist will complete assessments, and keep process notes. The music therapist will analyze and summarize this data. Results will be available in the form of a written research project.

6. There will be opportunity for staff, family, and researcher to collaborate throughout this project. In-services may be held with staff to familiarize them with the project and to disseminate results. This is an exploratory study and any techniques or materials developed in these sessions that may be useful to the staff will be shared in the form of in-service.

7. Your facility will be responsible for providing access to patient, collaboration with staff, and treatment space. Sessions can be held bedside, in day area, or office space, and will be held at times that are convenient for the family, patient, and staff. You may have some equipment already in place, such as tape player or musical instruments that could be utilized in this project.

8. It would be useful to identify a key person to be my primary contact for this project, either a social worker, activity director, or nurse.

9. I will be providing consent forms and release forms for both the family and patient to sign. I will keep staff informed of scheduled times of sessions.

This project should benefit not only the patients and family involved, but also the staff working with these patients. I am looking forward to this collaboration and will seek to encourage feedback from your staff regarding ways to maximize benefits to all parties concerned.
I need your written consent to proceed with this project.

I, ________________, Administrator of ______________________, do hereby give my permission to proceed with the study described above. I understand that my facility will provide access to patient and medical record, space for treatment, and opportunities for collaboration with staff. I understand that results will be shared with staff in the form of in-service.

Patients participating in study:________________________________________________________

________________________________________________________

Proposed dates of study:____________________________________________________________

Proposed date, time, and location of sessions:__________________________________________

________________________________________________________

________________________________________________________

________________________________________________________

Contact person:______________________________________________________________

Proposed in-service dates:________________________________________________________

________________________________________________________

Music Therapist/Researcher Date

_________________________________________ Date

Administrator
APPENDIX B
CODING PROCESS – SAMPLE

TRANSCRIPT

3/31

Connie/ Mary JO  Session I

Mary Jo is a slender, white-haired, well-groomed white female, 72 years old. She has a constant drool from the right side of her face which has been affected by stroke. She carries a Kleenex with her constantly which she rarely uses to wipe the saliva. She constantly twists and folds the Kleenex. She is attractive and soft-spoken. She responds to greetings with eye contact and smile.

Our session begins with an introduction: Mary Jo and Connie are talking, there is no eye contact. Mary Jo speaks in a vague tone of voice.

C= Carol, CT= Connie (daughter), MJ= Mary Jo (Mother)

Original Notes in Margin Are Indicated in Closed Caption Bold Letters {

{GREETING}
C:  My name is Carol
MJ: (Responds with eye contact and big smile).
     Uh-huh. Carol. It's nice to meet you.
C:  I brought my guitar today so we could do some music.
MJ: You did bring?
C:  Yes. It is right here.

{POSITIVE RESPONSE TO MUSIC}
MJ:  Good! (Smile)
     Our pastor’s wife is a pianist, so beautiful, and she had a guitar.

{INABILITY TO CHOOSE SONG: WORD FINDING DIFFICULTY}
C:  Would you like to start with a hymn? Would you like to sing Amazing Grace?
MJ:  Listen, I don't know. I want her to be the guide.
C:  It might be nice to start with. You can just listen if you want to.

{DISORIENTATION TO TIME}
MJ:  They'll like (nods her head) especially the students.
C:  I sang and Connie watched her Mother
     I be there are a lot spiritual songs that you have sung with your students

{SPEECH PATTERN: WORD FINDING DIFFICULTY}
MJ:  Well, there have been. Children have been great, there have been so many, chat, that, especially in college.
     (This is a typical example of speech that just fades out)
C:  (Sang "He's Got the Whole World In His Hands"
     Connie primarily watches her Mother who is watching me.

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I ask "Who else has he got in his hands?" and when I didn't get a response I sang "Little Bitty Baby"."
What else could we put in that song?

{RESTLESSNESS}
MJ:  I don't know (starting to get restless, sits up in her chair)
C:   Some people say "He's got the wind and the rain"
     (As I begin to sing she settles back a little bit, then interrupts the song)
MJ:  He, they're supposed to, but I think it's changing too quickly
C:   Right! He can keep the wind and the rain, let's keep the sunshine.

{MOTOR RESTLESSNESS: WANDERING}
MJ:  I've just got to walk a little bit. Can you get this Connie?
CT:  What do you need?
MJ:  I'm going to walk around the room.
C:   You want to walk around a little bit?
MJ:  (Mary Jo rises with some assistance from Connie for balance).
CT:  (Connie looks concerned)

{IMPROVISATION}
C:  I improvise a walking theme:
   Walking, walking, Walking, Walking, See the pretty grass, and see the pretty trees
   Walking, Walking, Walking, Walking, See the pretty grass and see the pretty trees
   (Mary Jo returns to her seat)
   Walking, Walking, And thank-you for the sunshine that comes out today
   (Mary Jo is smiling as she sits down)
   Chased away the clouds today Thank-you, Thank-you,
   Thank-you for the sunshine Thank-you for the flowers
   Thank-you for the grass, Thank-you for the sunshine.

{POSITIVE COMMENTS ABOUT MUSIC}
MJ:  You've been playing very long?
C:   Since I was in high school. I started playing music in the second grade.
MJ:  It's good. It's very, very good.
C:   Thank-you
     And you played music, too?
MJ:  No, I didn't. I pick a little bit but not anything even half great.
C:   Did you use music with your classes?
MJ:  No, I teach the 4th through the 8th.
C:   So you teach what subject? You teach English?
MJ:  Just a number of...It's an all...I don't know what you call it.
CT:  Well, you taught reading
MJ:  Yeah. We had a reading lab.
CT:  In junior high
C:   That's right. That's important.

{DISORIENTATION TO TIME}
MJ:  It is. When you think I can't stand this any longer. And they take it with spells...and they
     have all kinds of problems. They've done real well with that. But all the problem isn't with
     the students. And there's more to it...than just going to school and then coming home.
C:   Right. Helps to have the parents teaching them to read, too, doesn't it.
MJ:  Well, I'm not sure that they do in most places... and they love the machines and
     things that they have there...accessories.
C:   They learn on computers, now.
MJ:  I haven't even started on those, have you?
C:   Yes. They've taught us computers.
     (Sang "Jesus Loves the Little Children")
     (Mary Jo did not respond, so I cut this song short)
CT:  Want to sing with Carol?
MJ:  I can't, but you all do.
C:   (Tried, "You Are My Sunshine")
     (Mary Jo blows her nose, no eye contact)
     (To Connie) What songs have you heard your Mother sing?
CT:  I don't really remember any except for the hymns from church. Her favorite... Do you remember your favorite song, your favorite hymn?

{INITIATED SONG REQUEST}
MJ:  I like Amazing Grace
C:   Let's try that one
     (Mary Jo watched quietly as I sang, Connie watched her Mother)

{SINGING}
C:   Want to sing with me?
     (Mary Jo and Connie both joined in. Mary Jo sang most of one verse. Mary Jo got up and walked. Connie looked concerned. Mary Jo came back and sat down.)
     Join us on the first verse again.
     (Mary Jo mouthed the words, she is picking at the Kleenex she holds)

{WANDERING}
MJ:  My legs are going to sleep. I've got to get up.
     (Connie assists her)
     Your arms are warm
C:   Are you cold? I can adjust the fan. (I get up and adjust fan)

{CONNIE TAKING MORE ACTIVE ROLE: SUGGESTING SONGS HER MOTHER KNOWS}
CT:  Do you remember the song you used to really like: "Fill My Cup Lord".
     Guides Mary Jo back to her seat.
C:   I may have to find it. If you sing a verse, I'll see if I can follow.
CT:  I'll have to bring it from home. I don't remember all the words.
MJ:  Do you have it..is it...
CT:  I have it at home, the music at home. I'll bring it.
     She might know "In the Garden"
MJ:  Oh I'm sure she does.
C:   That one I'll definitely have to look up. A lot of people like that one.
CT:  (Connie takes lead, and I accompany her. Mary Jo sings with us.)
MJ:  Seems like I just can't get settled.
CT:  That's all right. It's late in the afternoon and sometimes that's...
C:   (I start singing Kum-Ba-Ya)
CT:  Remember that one?
     (Connie sings along. Mary Jo stares at her hands and repeatedly folds Kleenex)

{SOOTHING ENVELOPE OF SOUND}
     (There is a sense of sharing, surrounding Mary Jo in an envelope of soothing sound. Even though she is passive, she indicates that she is taking it in...)

{POSITIVE COMMENT}
MJ:  That's pretty.
CT:  Do you have some wiping material
MJ:  I'll get you some in a minute.
C:   What was that?
C:   It's called Kum-Ba-Ya
MJ:  It's getting dark
C:   No, the sun just went behind the clouds
     Do you know some of those songs like "Give me a home where the buffalo roam (Home on the Range)
{SINGING}
(Mary Jo joins in singing)
Segue into "There's No Place Like Home"
I continued with "Somewhere Over the Rainbow"
(There was not much response from Mary Jo. She was distracted by a noise outside the room toward the end of the song).
I try "She'll Be Coming Around the Mountain".
(Mary Jo joins in singing, she seems to be attracted by the change in meter)
(Connie gets up to get Mary Jo a Kleenex, Mary Jo gets up to go with her. Connie explains that she was going to get a Kleenex).
{DISORIENTATION TO TIME/PLACE}
MJ: It seems so unfair to think that it's so high and costs so much that you have to curb paper.
C: Uh-huh. A lot of things...
MJ: They really are.
I want to go cause I'm cold.
C: Are you cold?
MJ: Yes, I am.
C: Let's sing one last song than we'll say goodbye.
I've enjoyed...
(Mary Jo comes back to seat, stumbles slightly, and apologizes)
What would you like to sing?
MJ: I don't know.
C: You like those lively ones
MJ: Yes. I do.
C: Let's sing "Oh Suzannah"
(I start singing and then change key, commenting that is too high)
CT: I don't know those words
(Mary Jo mouths the words)
MJ: That's nice
C: I go into "When the Saints Go Marching In"
(Mary Jo continues to mouth the words, sings. She is still staring at her hands and folding Kleenex)
MJ: I know now, when I asked you about home, Well, how long did you stay there today?
CT: How long did I stay at home? Oh a few days, and then I came back up here.
{DISORIENTED TO TIME}
MJ: And she didn't live, oh but a mile, from the place where I lived. But I don't know what all she did. But I looked up and saw her, it almost shocked me to death. I guess I can forgive her.
CT: You guess you can forgive me (touches Mary Jo's hand and laughs)
MJ: Cause when they come they either come to fix up their house, and move this, or do that. It'd be a nice place for them to come. (Laughter)
C: It's nice to have your family with you.
MJ: Especially when they are a good ways and you don't see them very often.
MJ: Does everybody have a sweater on but me?
C: Yes. I think so. Do you have a song you'd like to end with?
CT: No, I can't think of any right now.
{POSITIVE STATEMENT}
MJ: It was real nice of you to do this.
C: We'll do it again, too.
MJ: That would be fine. That's real, real good.
CT: Do you know that "Whisper a Prayer in the Morning?"
MJ: You don't have the music to it?
CT: That's the one your Sunday School class always sang, "Whisper a Prayer in the Morning", or "There's a Sweet Holy Spirit in this Place". Do you remember that one?
MJ: Yeah. I had forgotten that.
CT: Well, I'll bring those and share them with Carol.
MJ: You have more than one don't you?
C: Let me just make up a Goodbye Song:
    It's time to say Goodbye
    (Shook hands with Mary Jo)
    It's time to say Goodbye
    Thank-you for the music, the singing, and the laughter
    It's time to say Goodbye
CT: That's a neat song you just made up. She's a composer on the spot.
MJ: That's marvelous
C: I segued into "Goodnight Ladies"
MJ: That's really nice and I appreciate your coming
C: We'll meet again
MJ: Yeah!
CT: Well, is it about time for you to go back and eat dinner?
    I think it is.
MJ: What time is it?
CT: About five minutes after five. You want to give me part of that tissue and I'll hold it for you?
MJ: It doesn't make much difference.
CT: (To Carol) We might want to reconsider the time if we can.
C: Yes. Depending on your teaching schedule.
CT: Yes

END
APPENDIX C

SUMMARY OF THEMES

SOCIAL AND EMOTIONAL ISSUES FACED BY FAMILY CAREGIVERS
(Themes Identified in Initial Interview with Family Caregivers)

1. Grief and Loss
2. Role Reversal
3. Personality Changes
4. Loss of Communication
5. Loss of Recognition
6. Guilt
7. Helplessness
8. Anger, Resentment
9. Embarrassment, Shame
10. Depression
11. Empathy for the Loved One With Dementia
12. Intergenerational Stress
13. Time Constraints
14. Financial Burden
15. Fear of Inheriting Dementia
16. Fear of Future Dependency
17. Fear of Aging Process
18. Unresolved Personal Issues With Person With Dementia
19. Must Turn Over Care of Loved One to Persons They Initially Don’t Know

STRENGTHS OF FAMILY CAREGIVERS

1. Ability to Appreciate Things Their Loved Ones Can Still Do
2. Sacrifice/Sense of Fulfillment
3. Faith
4. Ability to Find Joy in Daily Interactions With Loved One
5. Maintenance of Sense of Humor
CRITERIA FOR HONORING THE LOVED ONE WITH DEMENTIA
(Moments When Honoring Was Observed in Video Tapes)

1. When music therapist and/or caregiver listened to the loved one with dementia.
2. When the music therapist used eye contact, gentle touch, and the unique qualities of music to bring the loved one into an awareness of her surroundings and what was happening in the present.
3. When music was chosen that was meaningful to the loved one because of past associations.
4. When the loved one was supported in verbally expressing feelings, thoughts, and associations elicited by music.
5. When the loved one was encouraged to express herself through music, by singing, composing lyrics, or exploring instruments.
6. When music was used to facilitate creativity, humor and playfulness.
7. When music was used to soothe and comfort the loved one.

CRITERIA FOR EMPOWERING THE FAMILY CAREGIVER
(Moments When Empowering Was Observed in Video Tapes)

1. When tender emotions were shared.
2. When physical touch was used to express affection.
3. When the family caregiver witnessed their loved one actively engaged in expressing themselves through music.
4. When the family caregiver took an active role in choosing music and meeting their loved one’s needs on a moment-to-moment basis.
5. When the family caregiver was able to soothe and comfort their loved one.
6. When memories of past experiences and events with their loved one were stimulated by association through music.
BENEFITS OF MUSIC THERAPY

Benefits For the Loved One With Dementia

1. Music overcomes sensory and auditory processing obstacles.
2. Music provides moments of connection with the present
7. Music provides opportunity for goal-directed behavior and a sense of accomplishment.

Benefits for the Family Caregiver

1. Music therapy reduces the sense of helplessness.
2. Music provides an additional support person for the caregiver.
3. Music provides a collection of positive memories.
4. Music provides opportunities for positive interaction during extended family visits.

Enhancing the Relationship Between the Family Caregiver and the Loved One with Dementia.

1. Music reduces isolation and loneliness.
2. Music provides glimpses of previous level of functioning and former personality.
3. Music provides opportunity for humor.
4. Music provides spiritual inspiration.
5. Music provides opportunities for physical interaction and affection.